

# The Social Meanings and Implications of the Beta- Thalassaemia Trait amongst South Asian Women in England

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For my parents,

Mohammed and Khurshid Irshad

*The brightest stars in the sky*

## **ACKNOWLEDGEMENTS**

This thesis is dedicated to my children; Daaoud, Aqsa and Azfar. They have never in their lives seen me without a book or a laptop. The sacrifices they made by allowing me to work and their understanding (or resignation) have been truly humbling. I would also like to thank my family, friends especially Dr Chantelle Anandan and Vicky Hammersly and colleagues at the University of Edinburgh who have always been unwavering in their support - particularly during the more challenging times. In addition, I would like to take this opportunity to extend my gratitude to my friends Dr Lisa Clarke, Dr Naureen Ahmad and Ian MacDougall for their practical support in getting this thesis together and grappling with the formatting demons. My supervisors; Professor Simon Dyson and Professor Lorraine Culley have encouraged and supported me towards completing this thesis for which I am grateful.

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## **ABSTRACT**

The **AIMS** of this study are to: (1) To explore how South Asian women (those who have ethnic origins in India, Pakistan or Bangladesh) make sense of the beta-thalassaemia trait in the context of their everyday experiences and, in turn, how these experiences impact their identities. (2) To ascertain the extent of the assimilation and management of genetic information by women of South Asian origin. (3) To contribute towards the debate on the provision of culturally sensitive screening policies and the dissemination of genetic information and to analyse ways in which such policies can be improved.

**STUDY DESIGN:** A qualitative modified grounded theory study comprising of semi-structured interviews conducted in English, Urdu, Punjabi, Sylheti and Hindi. Five geographical sites were selected for the study: three in London, one in the West Midlands and a further site in Northern England based on their high density of South Asian populations as indicated by the 1991 UK Census data. Purposive sampling ensured diversity in participant backgrounds (e.g. socio-economic, religion, marital, child's health and age). Interviews were translated and transcribed by the researcher and the computer software NVivo was used to analyse the data.

**SAMPLE:** Forty-one South Asian women who had been diagnosed with the beta-thalassaemia trait and two haemoglobinopathy nurse specialists who undertook the role of counselling.

**FINDINGS:** The empirical findings revealed the importance of identity, faith, culture and diversity in how women managed the knowledge of the beta thalassaemia trait.

Common perceptions held by health service staff of South Asian women being homogenous in attitudes to prenatal diagnosis and termination; as subjugated to their husbands in decision-making; and as fatalistic because of their religious convictions were shown by this study to be misconceived. South Asian women actively managed their trait within the context of their everyday socio-cultural and religious experiences. For example, liberal notions of ‘informed choice’ were found not to take account of the institutional importance of motherhood for South Asian women living in the UK. Their experience of beta-thalassaemia trait was also mediated through relations of power, both within kinship networks and between family and health professionals.

In making sense of the genetic identities accorded to them by health professionals, they also re-interpreted, negotiated and contested the ethos of the screening and prenatal testing processes. The participants used power and positionality to relocate their sense of genetic responsibility away from the self onto others, employing geographical and cultural explanations to justify their apparent inaction in the face of biomedical expectations and assumptions.

**CONCLUSION:** Women acted according to their perceptions of how others would perceive them if their trait were to be disclosed and as a result they presented and constructed the trait in order to preserve the ‘self’ within the context of their everyday

life experiences which has implications for the delivery of appropriately targeted screening and health services.

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# CHAPTER ONE: INTRODUCTION

## 1.1 Overview of the chapter

This chapter will introduce the study and in doing so, it will provide the reader with an overview of the thalassaemias including, more specifically, beta-thalassaemia, which forms the focus of this study. The epidemiological and socio-cultural aspects of beta-thalassaemia trait ( $\beta$ TT) are discussed – both within a global and UK context, including screening and diagnostic processes of the disease and the treatments available. Finally, this chapter will conclude with an outline of this study and its aims and objectives.

## 1.2 The thalassaemias in context

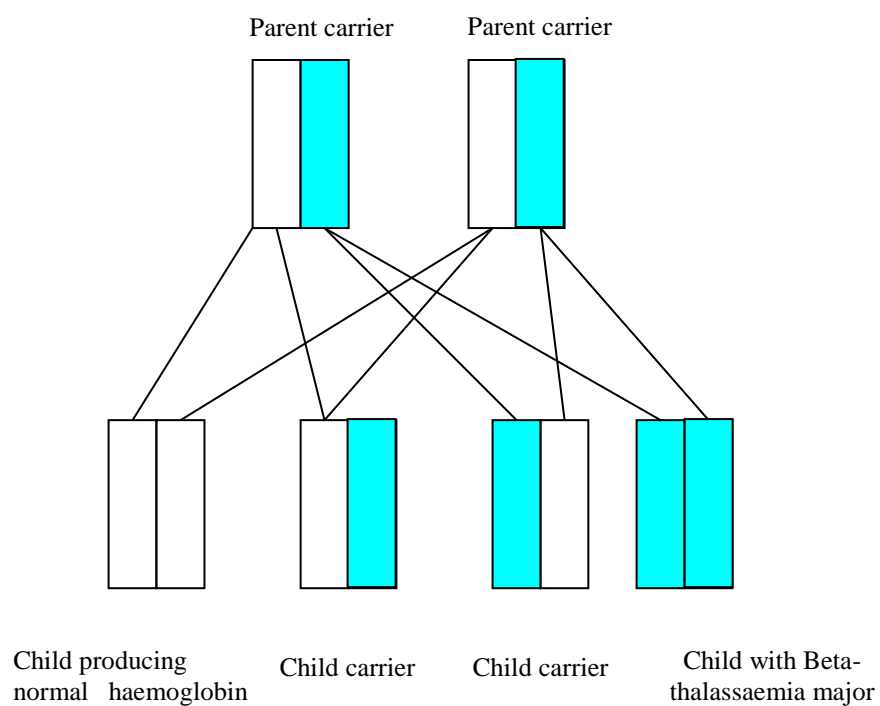
The historical developments which have led to the current understanding of thalassaemia in general have been aptly chronicled by Weatherall and Clegg (2001) and will, therefore, not be detailed in this study. Suffice to say, the thalassaemias are recessively inherited haemoglobin disorders which result in a reduction in the quantity of either the alpha or beta globin chain (Wiwanitkit, 2006) and can be classified as follows;  $\alpha$ ,  $\beta$ ,  $\delta\beta$  and  $\varepsilon\delta\beta$  thalassaemias (Weatherall and Clegg, 2001). Normal haemoglobin (Hb) of all types is made up of four globin-protein chains, which fold together to form a specific protein (a tetramer) which allows the binding of up to four molecules of oxygen ( $O_2$ ) and enables blood to perform its function of supplying oxygen to the body. In an adult, 98% of haemoglobin is Hb A, which is made up of two  $\alpha$  globin chains and two  $\beta$  globin chains (Weatherall & Clegg, 2001). The other 2%, Hb A<sub>2</sub>, is made up of two  $\alpha$  globin chains and two  $\delta$  globin chains (Weatherall & Clegg,

2001). Thalassaemia can range from mild to moderate to severe depending on the type and genes inherited. The most common types of thalassaemia are *alpha*, which is caused by a genetic deficiency in the synthesis of alpha-globin chains, and *beta*, which is caused by a genetic deficiency in the synthesis of beta-globin chains. In the homozygous state (where the gene carries two copies of the allele), Beta thalassaemia major ( $\beta$ TM) results in severe microcytic, hypochromic anaemia which, if left untreated, can lead to premature death because the blood cells are almost devoid of haemoglobin (Zani *et al.*, 1995).

### **1.2.1 The inheritance pattern of beta-thalassaemia**

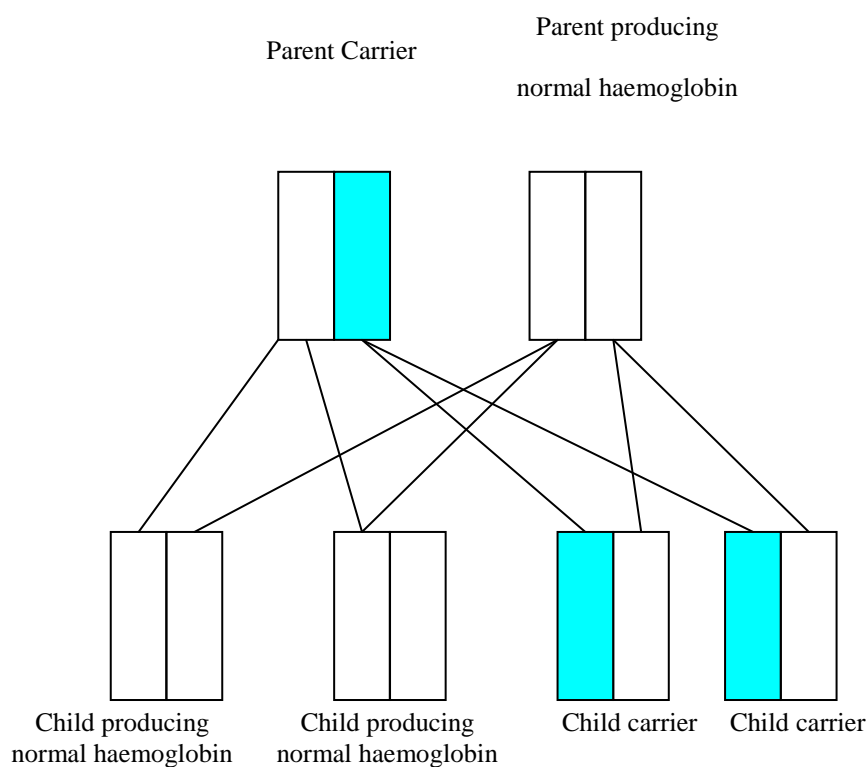
If both parents have  $\beta$ TT, then there is a 25% chance in *each* pregnancy that the child will inherit two beta-thalassaemia genes and will therefore have the full condition,  $\beta$ TM as illustrated in figure 1.

**Figure 1: Patterns of inheritance where both parents are carriers**



If one parent carries  $\beta$ TT and the other parent has genes associated with the production of normal quantities of haemoglobin, there is no chance that the child will inherit  $\beta$ TM. However, as shown in figure 2, there is a 50% chance in each pregnancy that the child may inherit the  $\beta$ TT.

**Figure 2: Patterns of inheritance where one parent is a carrier**

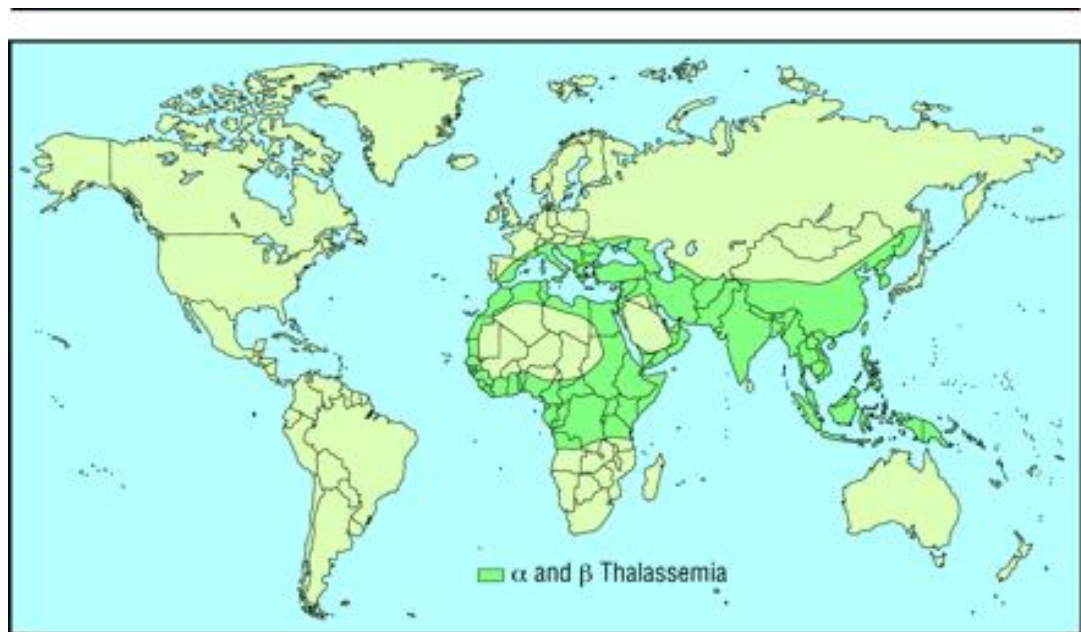


### **1.2.2 Epidemiology of beta-thalassaemia**

The thalassaemias are distributed across the Mediterranean region, the Middle East, the Indian subcontinent and throughout South-East Asia in a line stretching from southern China down the Malaysian peninsula to the Indonesian islands (Weatherall & Clegg, 2001) as illustrated in figure 3.



**Figure 3: The global prevalence of thalassaemia**



Source: Weatherall & Clegg: 2001:238

Beta-thalassaemia is very common in the Mediterranean, the Middle East, central Asia, the Indian subcontinent, Southeast Asia and North Africa. It can be seen from figure 3 that haemoglobin disorders are common in parts of the world where there is, or where there was historically, a high prevalence of malaria. Some research has suggested that  $\beta$ TT provide a strong natural protection against one of the most virulent types of malaria causing an organism, *Plasmodium falciparum*, which manifests itself by destroying red cells and resulting in high fevers and a high mortality rate (Modell & Darlison, 2008). According to Modell and Darlison (2008), thalassaemia carriers are protected by virtue of having smaller red cells which contain less haemoglobin than normal. As a result, the parasite uses up all the haemoglobin before it has finished growing, so it cannot spread

to neighbouring cells. Other than the protection against certain types of malaria, there is also emerging evidence that carriers of the  $\beta$ TT may be protected against heart disease during adulthood (Modell and Darlison, 2008).

Although, the process of migration and settlement has resulted in the thalassaemia gene appearing in more diverse populations in the West (Atkin & Anionwu, 2010), population, growth in the traditional thalassaemia belt has resulted in higher incidences within the affected populations (Modell and Darlison, 2008). Current global estimates suggest that the number of  $\beta$ TM births stands at 56,100 per annum with approximately 3,000 of these dying per annum as a result of iron overload (Modell and Darlison, 2008).

### **1.2.3 Thalassaemia in the United Kingdom**

This section will provide a UK focus on beta-thalassaemia. Although data collected during the 1980s showed approximately 16  $\beta$ TM births in the UK per annum (Constandtinides, 1987), current thought is that there are around 20 new cases of  $\beta$ TM each year (personal communication, Bernadette Modell, 2008) mainly from Cypriot and Pakistani communities (Modell & Anionwu, 1996; Zeuner *et al.*, 1999). More recently, the NHS Sickle Cell and Thalassaemia Screening Programme estimated that there were approximately 700 people with  $\beta$ TM and an estimated 214,000 carriers in 2008 (Anglin & Streetly, 2007). Again, the highest prevalence of beta-thalassaemia was found among high risk communities such as Cypriots and South Asians as highlighted in table 1 (derived from Anionwu and Atkin, 2001:12).

**Table 1: Carrier frequency by ethnic group**

Haemoglobin Type	Ethnic Group	Estimated Trait Frequency
Beta Thalassaemia trait	Cypriot	1:7
“	South Asians	1:10-30
“	Chinese	1:30
“	African-Caribbean	1:50
“	White British	1:1000

The Pakistani population in the UK has come under particular scrutiny due to the higher risk of producing children with  $\beta$ TM, especially within consanguineous marriages (Modell *et al.*, 2001), as illustrated in table 2 (derived from Anionwu and Atkin, 2001)

**Table 2: Patterns of inheritance in Pakistani marriages**

Pakistani marital status	Chance of trait partner (%)	Chance of thalassaemia major child (%)
Unrelated	4.5	1.2
Related	12	3.0
Consanguineous (first cousin)	16.5	4.1

When combined with at-risk data, consanguinity has frequently been employed as a basis for the persistent belief among some health care professionals (and politicians) that consanguineous marriages are largely responsible for the higher risk of genetic disorders affecting primarily the Pakistani populations (Ahmed *et al.*, 2000b). However, although consanguineous marriages are strongly preferred in some parts of Pakistan and not others there is very little data on the prevalence of such marriages in the UK. As such, some researchers claim it is unrealistic to make assumptions about cultural practices such as consanguinity being attributable to birth outcomes (Ahmed *et al.*, 2000b) without taking into account the socio-economic, migratory and ante-natal service provision factors (Ahmad & Bradby, 2010).

Ahmed *et al.* (2000b) reiterate that, contrary to assumptions generally held by the healthcare professions, the literature on consanguinity and birth outcomes is at best ambiguous and often contradictory. The oft-quoted carrier and implication frequencies are usually based on estimated frequencies (Ahmed *et al.*, 2000b) and very often neglect to take into account the poorer quality of antenatal care experienced by South Asian women as a contributory factor to poor birth outcome (Ahmad, 1994).

#### **1.2.4 Screening for thalassaemia**

A commitment to haemoglobinopathies was made for the first time in The NHS Plan 2000 (Department of Health, 2000) which outlined a strategy to establish a National Antenatal and Neonatal Sickle Cell & Thalassaemia Screening Programme. Prior to the UK Government's universal screening policy, screening was mostly conducted on an *ad*

*hoc* basis using either ethnicity-based data where available, or name recognition software. The problems of identifying ethnic groups correctly were recognised and raised as far back as 1998 by Dyson (1998), who discussed the unsatisfactory nature of both name recognition and covert universal testing. At the time that the research data for this study was being collected, there had been little progress in the issue of ethnicity classification and testing, as identified in Sedgwick and Streetly's (2001) article:

*"The important component of ethnicity to identify is an individual's ancestry. This information can only be obtained by questioning the individual. Ethnic group classification e.g., using census categories, is inappropriate for making screening decisions. A validated standard ethnic origin screening question for identifying individuals of non-northern European origin is required."*

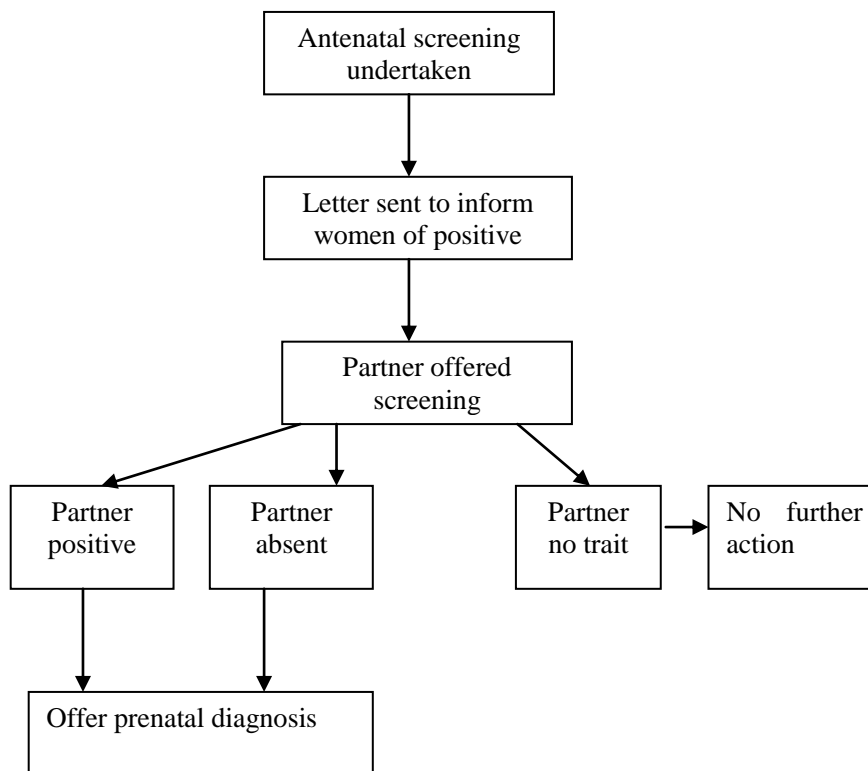
Source: A survey of haemoglobinopathy screening policy and practice in England (Executive summary: 1)

In order to overcome these issues and to encompass the dynamics of self-perceived and practitioner-perceived ethnic identities, an ethnic question was developed, piloted and evaluated by Dyson et al (2006) as a screening tool to identify individuals at higher risk from specific haemoglobinopathies which then provided the basis for further research into this issue, for example the 'Evaluation Of Family Origin Questionnaire' (ETHNOS Research and Consultancy, 2006). After training, midwives began to utilise these screening questionnaires, enabling a wider proportion of women at risk of producing children with sickle cell disease and thalassaemia to be identified and thus screened (Dyson *et al.*, 2007). Evaluations from these studies were incorporated into the NHS Sickle Cell & Thalassaemia Screening Programme which had been initiated in 2002 in order to provide a more comprehensive, universal system of screening programmes

throughout England. The remit of the Programme was to provide systematic screening which would overcome issues of ethnic targeting and identify thalassaemia carriers early enough to aid decision-making in the management of an affected pregnancy.

Consequently, the discovery of an 'at risk' couple (where both partners have the trait) during the antenatal screening process will prompt the offer of further prenatal tests subsequent to which the couple are informed as to the diagnosis of the foetus. The assumption is that the couple will then be in a more informed position on how to manage that particular pregnancy, opting for continuation or termination. The following flowchart (Figure 4), which I devised after discussions with healthcare professionals at the forefront of antenatal and prenatal testing, illustrates the antenatal screening process in more detail:

**Figure 4: The antenatal screening process in general**



Although this diagram illustrates the theoretical process in general, there are women who do not undertake various components of this process as they or their partners may not be in this country in time for the relevant tests to take place. Also some women may not undergo the screening process until later on in their pregnancies which then impacts the decision making process of whether to undergo prenatal diagnosis. Dormandy et al (2008) in their study found that it is the 'system' that is perhaps responsible. Although, 74% of women in her study had consulted their GPs before 10 weeks' gestation, fewer than 5% of women were screened before the target time of 10 weeks, thereby reducing the time span for decision making in the possible termination of an affected pregnancy.

### **1.2.5 Preventing beta-thalassaemia major births**

Many women in this study were diagnosed with the  $\beta$ TT prior to the advent of the NHS Screening Programme and universal/routine antenatal testing. In such cases, partners of diagnosed women were then invited for testing to ascertain the couple's at risk status. If both are diagnosed as carriers then prenatal diagnosis will ascertain the status of the foetus.

Writers such as Alfirevic et al (2003) have highlighted the tight timeframes of conducting prenatal tests as a major disadvantage, conflicting between obtaining a valid test result and preventing an affected birth in the early stages of pregnancy. However, guidelines issued by the Royal College of Obstetricians and Gynaecologists (Royal College of Obstetricians and Gynaecologists, 2005) recommend that amniocentesis should normally be undertaken after 14 completed weeks of gestation and chorionic villus sampling (CVS) after 10 weeks gestation to avoid potential complications such as miscarriage, which leaves little time for decision making before the legal upper time limit of 24 weeks for the termination process. Regardless of this, prenatal testing generally does carry a risk of miscarriage, which stands at 1% for amniocentesis and 3% for CVS (Royal College of Obstetricians and Gynaecologists, 2005). A discussion of the techniques is summarised below:

1. Chorionic villus sampling (CVS): this method involves obtaining a small sample of the chorionic villi (placental tissues), either by passing a thin needle through the wall of the abdomen (transabdominal), or by passing a small tube through the vagina



(transvaginal) and the neck of the womb (cervix). The needle, or tube, is moved to the site of the placenta under the guidance of ultrasound scanning. From the cells obtained during the process, a chromosome (genetic) analysis can be carried out, and the results are said to be usually available within 10 to 14 days (Royal College of Obstetricians and Gynaecologists, 2005).

2. Amniocentesis: again using ultrasound as a guiding tool, a syringe is used to remove a small sample of amniotic fluid from the amniotic sac for analysis which, when cultured, can be analysed to obtain genetic information (Royal College of Obstetricians and Gynaecologists, 2005).

3. The final method is foetal blood sampling where blood is obtained from the foetal cord at around 17-18 weeks of gestation. Utilised when other procedures such as CVS are considered unsuitable, or access to the placenta is difficult, or when the DNA test cannot determine the exact DNA profile of the baby, it has the added advantage that an affected baby will have little or no adult Haemoglobin HbA thereby making  $\beta$ TM easier to detect (United Kingdom Thalassaemia Society, 2008). This process also has a miscarriage rate of 1% which is equal to that of amniocentesis (United Kingdom Thalassaemia Society, 2008).

Subsequent to prenatal tests, the most viable option available to the couple diagnosed with an affected foetus is the termination of the pregnancy. However, this option in itself presents a myriad of social, religious and personal issues. The ideals upon which the ethos of the screening process is founded can be seen as potentially conflicting,

dependent on the position that an individual adopts in relation to medicine and/or the value of a disabled life. The emphasis placed within the medical model is of screening as a process of informed decision-making towards the management or termination of a pregnancy that is at high risk of disability such as  $\beta$ TM (Hallowell, 1999; Petersen, 1998). This model has clashed with the ideals of groups that espouse disability rights and who view the presumption of termination as a form of eugenics. They suggest that screening programmes compromise the right to life for people who have disabilities and that the universal availability of such screening programmes makes society less tolerant of those with a physical disability (Shakespeare, 1998). As a result, for many disabled people, the message implicit in the practice of termination based on genetic characteristics is that it is better not to exist than to have a disability. The birth of a disabled person is therefore viewed as a personal, economic and social burden (Kaplan, 1994) and successful initiatives that have helped prevent such births are held up as examples of good practice, such as the public awareness programmes in the Mediterranean and some Middle Eastern countries (Angastiniotis *et al.*, 1986). Religion also influences the issue of termination in Hinduism, Sikhism and Islam. Although much attention has been focused on Muslims in this respect, all the major doctrines seem to follow the same sanctity of life thread as each other to varying degrees. The Hindu doctrine suggests that Hindus must revere all life and follow a policy of non-harm (ahinsa) to living creatures. Hindus may therefore object strongly to any involvement in the termination of pregnancies, believing that pregnancy termination sends the soul back to the cycle of rebirth. However, the exception to this is where the termination is carried out to save the life of the mother (Jootum, 2002). Sikh doctrine

also prohibits the termination of pregnancy unless it is to save the life of a mother (Gatrad *et al.*, 2005). Debate among Muslim scholars has seen a number of Islamic states such as Iran, Turkey and Saudi Arabia issuing fatwas (rulings based on the teachings of the Prophet) that have suggested that the termination of a pregnancy for an abnormal foetus is permissible before 120 days of gestation, when the soul begins to breathe (ensoulment). Nevertheless, there is little evidence that such fatwas have made much difference in countries such as Pakistan, or even the United Kingdom, in the management of affected pregnancies. It has to be pointed out that the issue of a fatwa *per se* may not be enough to persuade individuals with affected pregnancies to consider termination. Furthermore, variability of the influence of fatwas can be illustrated by the case of organ donation. In an attempt to encourage more Muslims to register for organ donation, the UK Islamic Shariah Council issued a fatwa in 1995 supporting organ transplantation as a means of relieving pain or saving life. Despite this, there is no evidence that this has increased the number of organs donated by the Muslim population (see Baines *et al.*, 2002; Darr & Randhawa, 1999). It would seem that fatwas are interpreted by individuals according to their perceived beliefs and within the context of their life experiences, religious adherence and socio-demographics (Ahmed *et al.*, 2008) and alternatives such as IVF and preimplantation (where the fertilised embryo is screened before implantation) diagnosis may be seen as better alternatives to terminating an affected pregnancy.

### **1.2.6 The clinical management of beta-thalassaemia major**

Typically, treatment consists of systematic blood transfusions every 4-6 weeks for the duration of the patient's life, which can lead to further complications such as iron overload as the transfused red cells break down over a longer period of time. The accumulation of iron can result in major organ damage, specifically to the heart, pancreas, kidneys or liver and even death (Weatherall & Clegg, 2001). This excess iron is then removed from the body by way of chelation therapy, which can be administered either subcutaneously and/or orally. The subcutaneous intervention consists of a drug (desferrioxamine) administered via a battery operated pump, or shorter subcutaneous infusions where the medication is prepared in a syringe and then attached to tubing at the end of which is a (butterfly) needle, which is then inserted into the space just below the skin. The pump intervention, considered more invasive, generally consists of 10-12 hour sessions for 5-7 nights per week (Olivieri, 1998). Although time consuming and painful, this treatment has improved survival for patients with thalassaemia especially through the reduction of cardiac overload (Borgna-Pignatti *et al.*, 2004). However, even though survival rates have increased well into the 40<sup>th</sup> year, (Clarke *et al.*, 2010), the intense nature of this intervention does lead to quality of life and compliance issues especially during salient times such as the transition from childhood to adolescence. This has resulted in indifference or rejection of therapy by many teenagers (Atkin & Ahmad, 2000b), which may lead to iron overload resulting in major organ, such as heart or liver, failure (Porcu *et al.*, 2007). Medical advances such as the advent of oral chelation therapies, for example deferiprone and deferasirox (Roberts *et al.*, 2007) have been shown to improve compliance with treatment regimes

and are as effective as subcutaneous chelation (Lai *et al.*, 2010; Tanner *et al.*, 2008). It has to be highlighted at this point that, although oral chelation has taken much of the difficulty out of the iron removal process, it is not without its controversies; issues regarding the safety of deferiprone arose in the late 1990s because of an observation of hepatic fibrosis during a clinical trial (Olivieri, 1998). Other observed adverse effects include gastro-intestinal reactions and zinc deficiency (Naithani *et al.*, 2005) and, in some cases, a splenectomy is required to slow the rate of red cell destruction, consequently resulting in the reliance of penicillin to prevent the onset of infections. More recently, advances in haematopoietic stem (bone marrow) cell transplantation have offered the possibility of a cure. However, a major problem has always been the lack of a compatible sibling donor for the majority of affected patients (Gaziev *et al.*, 2008). Recent technological advances have overcome this limitation by enabling transplants from unrelated volunteer donors with results comparable to those obtained from a compatible sibling (Gaziev *et al.*, 2008), which will no doubt impact the uptake of such techniques to cure  $\beta$ TM.

### **1.3 Managing beta thalassemia major as a long-term condition**

Technological advances in the treatment of  $\beta$ TM especially in specialist Sickle Cell and Thalassaemia Centres and the resultant increase in life expectancy has led to the potential for  $\beta$ TM to be regarded as any other long-term chronic condition, for example diabetes. Policies designed to enable proactive self-management of long-term chronic conditions began in earnest with the election of a new Labour Government in 1997. The Labour Government's interest in the economic and NHS resource impact of both an

ageing and increasingly rising population with long-term conditions led to a series of reforms beginning in 1997 with the White Paper, *The New NHS: Modern, Dependable* (Department of Health, 1997) which set in motion a programme for restructuring the NHS including the creation of bodies such as NICE and National Service Frameworks for the management of (typically) singular conditions such as heart disease and diabetes (Taylor & Bury, 2007). Many other initiatives followed such as the White Paper *Saving Lives: Our Healthier Nation* (Department of Health, 1999) which recognised that patients with long-term chronic conditions are better skilled at symptom recognition and management by virtue of living with the condition and can therefore self-manage their conditions with the support of health care personnel.

Supporting patient participation in healthcare is seen by the government as a key mechanism to improve patient outcomes and reduce healthcare costs and various policy drivers led to the formation of policies and processes which enabled patients to become partners rather than mere receivers of healthcare. One such process is the Expert Patient Programme (EPP) (Department of Health, 2001a) where patients and carers are trained (and thus empowered) to better manage their long-term conditions through education programmes delivered by peers who have the same chronic condition. Along with self-management and disease management there is a recognised need to improve care for people with complex needs which was facilitated by the introduction of personalised case management through newly appointed clinical specialists. *The NHS Plan* (Department of Health, 2000) highlighted the need for trained nurses to provide proactive case management for patients who had potentially complex long-term

conditions such as  $\beta$ TM. These nurse specialists, better known as community matrons (The Department of Health, 2004a) deliver a personalised care plan to provide ‘*a more holistic approach to care...co-ordinating health and social care provision with the overall aim of promoting maximum function, independence and improved quality of life*’ (Carrier, 2009: 42). In essence, supporting people with long term conditions at home lessened the burden of unplanned hospital admissions (Department of Health, 2005a), freed beds and further emphasised the role of community matrons in coordinating services with other relevant health and social care professionals to ensure that patients’ needs were met (in conjunction with EPP initiatives) in order to promote better self-care and informed choices for patients living with a long-term condition and their carers (Lillyman *et al.*, 2009). In the case of patients who have  $\beta$ TM, case management typically involves teams of Consultant Haematologists, Clinical Nurse Specialists, Clinical Psychologists and Social Workers who work with the community matron to co-ordinate blood transfusion, chelation, compliance, benefits advice and potential complications that arise as a result of having  $\beta$ TM that have been previously discussed. Policy drivers designed to place the patient at the centre of proactive and equal healthcare delivery, such as the emphasis towards more personalised services (Department of Health, 2006) which will empower people to actively make healthier choices with regards to their health and healthcare (Department of Health, 2010a; 2010b) and the Darzi Review (Darzi, 2008). However, even then, there is a significant body of evidence which suggests that patients and carers from marginalised sections of society do not benefit from patient focused initiatives such as the EPP, as much as had been hoped (Greenhalgh, 2009; Lindsay & Vrijhoef, 2009; Stone *et al.*, 2005). This

may be due to many reasons and criticism has focused on issues such as the biomedical model those programmes follow, which then makes them inaccessible to deprived groups (Lindsay & Vrijhoef, 2009) as well as their uncoordinated and *ad hoc* method of delivery (Atkin & Anionwu, 2010).

Even though initiatives such as the EPP and involvement of community matrons are subject to criticism, as I have illustrated above, the essence of such programmes is that the combination of patient and carer empowerment, and medical advances in the treatment of  $\beta$ TM has the potential to lessen the negative impact on quality of life and outlook of women with  $\beta$ TT, especially those with  $\beta$ TM children. This may then change how they perceive themselves and, as a result, manage the knowledge of their potentially stigmatisable trait. If  $\beta$ TM can be discussed and managed in the same way as any other long term chronic condition such as diabetes then, theoretically, the stigma, impact and consequences of having a genetic trait may diminish over time.

## **1.4 Rationale for the study**

Being Pakistani and able to speak fluent English, Punjabi and Urdu, I became involved in advocacy work for the Pakistani community in East London. This involved accompanying members to health, education and welfare consultations and providing translation and interpretation. This experience led to my undertaking post-graduate study in social policy and then social science research methods. I then began searching for opportunities in which to develop my interest in ethnicity and health and



subsequently applied for and was awarded a research studentship in social understandings of a genetic disorder.

As indicated in table 1, people of South Asian origin are at high risk for carrying the  $\beta$ TT. In addition, within this group, Pakistanis are particularly considered to be at high risk of giving birth to children with  $\beta$ TM (Modell & Modell, 1990) as a result of practices such as consanguinity. Although there was research on how people perceive genetic disorders, much of it was focused on majority populations and there was very little information how women in these high risk groups (such as South Asian) process, comprehend and utilise genetic information. It was therefore imperative to gain an understanding of what a genetic disorder would mean to South Asian women who are typically under-represented or marginalised in mainstream and, more specifically, specialist (genetic) health services. In addition, it was important to ascertain how they made sense of and managed a hereditary condition such as the  $\beta$ TT with its potential consequences and implications in cultures which are both value determined with regards to expectations of females and pronatalist. It was hoped that this understanding would lead to ways of better delivering genetic information. The specific aim and objectives of the present study are as follows:

### **1.5 Aim of the study**

The aim of this study is to undertake an in-depth investigation of how South Asian women manage the knowledge of  $\beta$ TT and the meanings they give to the trait within

their social, cultural and religious contexts. In doing so, to better understand how this knowledge is assimilated into the women's everyday experiences.

## **1.6 Research Objectives**

In order to achieve the study's aim, the following objectives were undertaken:

1. To explore how South Asian women (those who have ethnic origins in India, Pakistan or Bangladesh) make sense of the  $\beta$ TT in the context of their everyday experiences and, in turn, how these experiences impact their identities.
2. To ascertain the extent of the assimilation and management of genetic information by women of South Asian origin
3. To contribute towards the debate on screening policies and the dissemination of genetic information and to analyse ways in which such policies can be improved.

It was acknowledged at the onset that this study would include an exploration of potentially sensitive and stigmatising conditions within a personal and socio-cultural context and this would require a researcher who had an element of 'insider' knowledge (Bhopal, 2000a; Sprague, 2005). My own background as a Pakistani Muslim woman fluent in the main South Asian languages and who had both research and advocacy experience in working with South Asian communities was deemed as providing me with the necessary skills to conduct this study. Although the issue of insider-outsider research is explored in greater detail in chapters four and five, it is sufficient to say here

that sharing significant similarities in languages, religious beliefs and aspects of culture would enable a sensitive exploration of this area of study (Papadopoulos *et al.*, 2004). At the same time, although I as a researcher felt that my situation as an insider to various degrees would facilitate this study, I was also aware of the issues of insider research and this is discussed in greater detail in chapter five.

## **1.7 Structure of the Thesis**

Chapter Two: sets out the demographics of the South Asian community in Britain. It provides an historical, socio-demographic, health and economic overview of the South Asian population in Britain.

Chapter Three: reports the existing literature on the socio-cultural aspects of health, illness, hereditary disorders and the management of illness. It also outlines religious and lay health beliefs as well as providing a reflection on the process and politics of health care services for BME populations and hereditary disorders.

Chapter Four: focuses on the epistemological approach to the study together with its limitations. The chapter will also provide the methodological approach adopted in this study, the ethics process by which clearance for the study was given, the sampling strategy and processes, the methods of data collection and the analysis of the empirical data including issues of validity, reliability and generalisability.

Chapter Five: will provide a discussion on the ethics of sensitive research. It will give an overview of issues such as definitions of sensitive research, issues in recruiting

minority ethnic populations for research studies, sensitive research and the interview setting, handling participant emotions and the researcher's position in the research setting.

Chapter Six: is the first of three chapters that present the findings of the study. This chapter will unravel the lived experiences of South Asian women who have  $\beta$ TT (some of whom may also be mothers of  $\beta$ TM children) in terms of their identities, perceptions of their own values, the women's discursive constructions of their trait and the potential impact of the trait upon some of the most valued roles they have in their own societies. These valued roles, of protecting the family honour and of childbearing, are tied up with general discourses of gender and power in wider society.

Chapter Seven: comprises the second analysis chapter and focuses on the stories of the women's experiences of the screening process as well as the factors that influence the actual practice of screening itself. It will ascertain the different periods when the women were diagnosed with the trait and the age/circumstance factors that interplay with the diagnosis settings. It will also ascertain how their screening experiences influenced their attitudes towards genetic testing. The chapter will also focus on cultural practices such as consanguinity and how perceptions of these practices by the wider society impacted upon these women and their testing experience. Finally, the chapter will attempt to unravel the complex dimensions of fatalism and how it directly correlates with the women's perceptions of the dynamics of screening.

Chapter Eight: comprises the final analysis chapter and will consider the way in which counselling is delivered. In addition to this, the chapter will focus on the delivery of genetic information. The communication of risk is examined with respect to women who may or may not have a sufficient command of the English language. It will also ascertain what the participants understood and how they utilised (or did not) the information they were given.

Chapter Nine: will discuss the main arguments drawn in this study. It will bring together the study findings on the perceptions and experiences of haemoglobin disorders and current health provision within the socio-cultural and religious context. I will then discuss the conclusion of the study and present health policy initiatives that will impact upon South Asian carriers as well as suggest further recommendations for policy and practice in service implementation and suggest avenues for future research.

## **CHAPTER TWO: SOUTH ASIAN COMMUNITIES IN ENGLAND**

### **2.1 Introduction**

The previous chapter explored the clinical and epidemiological aspects of the thalassaemias, particularly focusing on  $\beta$ TT, followed by an overview of the main aim and objectives of the study. This chapter will introduce the populations on which this study is centred – those of South Asian descent in England. It will then examine the specific issues facing these communities in terms of health, socio-economic issues and the current socio-political context and its impact on the experiences of being South Asian in Britain.

### **2.2 Classifying South Asians**

The evolving nature of classifications provided in the Census is perhaps an illustration of the problematic nature of ‘labelling’ people while retaining enough flexibility to incorporate the fluidity of personal identities. Although the term ‘South Asian’ has come to signify people originating from the Indian sub-continent, it may not be a concept that is recognised by people actually residing in India, Pakistan or Bangladesh. This formation of a collective identity has emerged as a consequence of migration in which a group of people coming from the same geographical region are presumed by the majority population to have a common language, culture, religion and so on. South Asian identity thus developed along similar lines to the concept of “pan Caribbeanization” (Harris & Winston, 1993) whereby the experience of racism and the

need to belong to a particular group played a prominent role in the development of the Caribbean identity. Early migration (detailed later in the chapter), resulted in settlement patterns which enabled people coming from the Indian sub-continent to amalgamate in clusters which were deemed necessary in a foreign and fairly hostile environment and enabled the facilitation of employment and accommodation with kin that had already settled in the UK.

The term 'South Asian', however, is not without its problems. As an ethnic classification, the term 'South Asian' has been criticised as being too inflexible and failing to recognise the diversity within this category. The original ethnic question in the Census 1991 included the category 'Asian' where a person could be classified as Indian, Pakistani, Bangladeshi, Chinese or any other ethnic group. This had evolved by the time of the Census 2001 whereby categories such as 'mixed' or 'any other Asian background' were included (Office for National Statistics, 2001). Nevertheless, criticisms prevailed about the continuing inflexibility of the classifications of these and other ethnic groups, such as 'Black African' (Aspinall & Chinouya, 2008) especially in the face of a growing heterogeneous population, which then resulted in consultation exercises on how ethnic classifications can become more inclusive in the Census 2011. The resultant proposed questions in the Scottish Census 2011, for example, seem to have overcome many of these criticisms (The Scottish Government, 2008) and have included ethnic classifications of 'Asian' 'Asian Scottish' and 'Asian British' including sub-categories of 'Indian', 'Pakistani', 'Bangladeshi', 'Chinese' and 'other' (The Scottish Government, 2008). Although not ideal, classifications such as these may

allow people to choose their own ‘perceived’ ethnic identification, thereby recognising the fluid nature of personal identities, perhaps in response to socio-political circumstances (Culley & Dyson, 2001). This is, perhaps, aptly illustrated by the current socio-political situation where many young Pakistanis may identify themselves as ‘Muslim Pakistani’ as distinct from say ‘British Asian’ in order to construct a sense of what it means to be a Muslim in a post 9/11 or 7/7 bombings environment in a Britain which they perceive as hostile to them (Choudhury, 2007).

In addition to the debate about classifying ethnicity, there is also a recognition that the concept of ethnicity has become the default explanation for poor health and social outcomes regardless of external factors such as inequality and deprivation, as highlighted by Ahmad and Bradby (2008:48) in the following excerpt:

*“Ethnic divisions do not exist in isolation from other social divisions. Many minority ethnic groups are subject to forms of social exclusion and marginalization. All too often, minorities’ predicament (poor housing, poor health and unemployment) is explained, not in terms of unequal access to resources and opportunities or discriminatory state and market institutions, but as a result of innate features of the groups themselves. Thus the minority’s disadvantage becomes racialized, that is, seen predominantly as something located in their problematic culture or biology. Such analyses often ignore the relationship between minority ethnic status and socioeconomic position.”*

As the above excerpt highlights, apportioning blame to the culture and behaviours of marginalized ethnic communities negates the impact of socio-economic deprivation on maternal health and poor birth outcomes. For example, South Asian women who give birth to children with hereditary or congenital anomalies are often criticised for poor birth outcomes which are viewed as a consequence of cultural practices such as

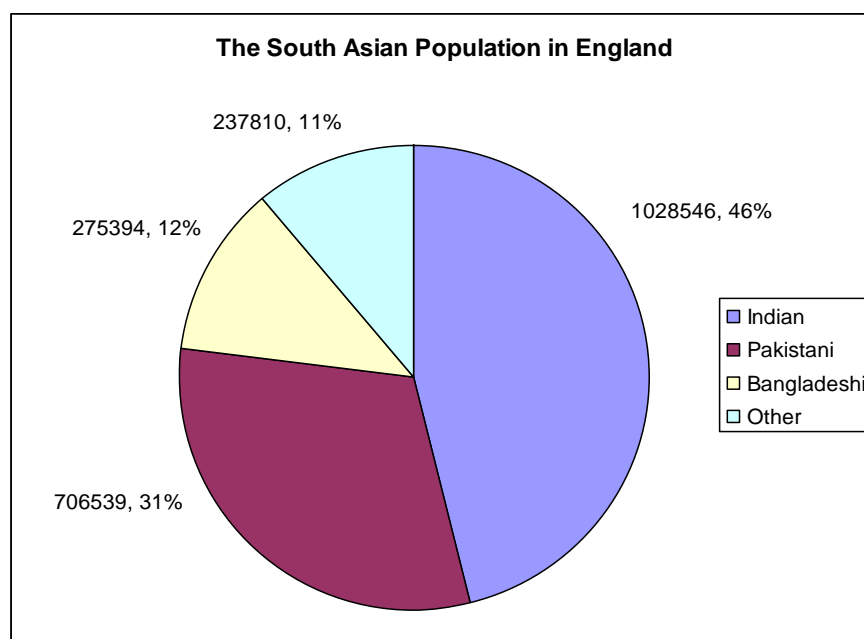


consanguinity rather than health care professionals looking to the prevalence of carriers of genetic anomaly within their communities (Ahmed *et al.*, 2000b).

## 2.3 The South Asian populations

The UK Census 2001 revealed that the majority of the UK's population is white (87%), which includes Eastern European populations. The black and minority ethnic (BME) populations comprise the remaining 13%. Within this BME cohort, almost half (49.6%) have their ethnic origins in India, Pakistan or Bangladesh (Office for National Statistics, 2001) as illustrated in figure 5.

**Figure 5: Countries of origin of the South Asian population in England**



(Taken from Office for National Statistics, (2003))

Figure 5 illustrates the South Asian population neatly categorised into countries of origin and therein lies the problem. Contrary to popular belief, the South Asian presence in this country is and always has been a heterogeneous affair as Singh (1994:9) has pointed out:

*“It is a popular misconception to place all people originating from India, Pakistan, Bangladesh and people with brown skin from East African countries in one category - Asian. To call them Asian makes the assumption that they constitute one homogenous group. Indians, Pakistanis and Bengalis are separate communities in themselves with many variations within them. It is important to remember that cultural, regional, linguistic and religious diversity amongst these groups is very significant.”*

Although the recognition of the heterogeneity of these populations has been slow in mainstream policy, there is a growing awareness among healthcare providers, for example, of the need not just for cultural competency in general but to recognise the diversity within these minority ethnic cultures and communities (Kai, 2007). Indeed, the term ‘super diversity’, as defined by Vertovec (2007:3) may be seen to be a more apt description as it recognises and incorporates:

*“[the] dynamic interplay of variables, including: country of origin (comprising a variety of possible subset traits such as ethnicity, language[s], religious tradition, regional and local identities, cultural values and practices), migration channel (often related to highly gendered flows, specific social networks and particular labour market niches), and legal status (including myriad categories determining a hierarchy of entitlements and restrictions).”*

The term ‘super diversity’ recognises that, even within the population of Pakistan for example, there may be people who do not speak the national language, Urdu, but rather local dialects such as Mirpuri, Pushto or Sindi, which can have major repercussions for health care providers in terms of interpretation and translation issues - issues which are discussed in greater detail in the latter part of the study. Suffice to say that although I have utilised this section to highlight the need to recognise the diversity within these populations, I will continue to use the term ‘South Asian’ to represent the original definition of people with ethnic origins in India, Pakistan or Bangladesh as all of these groups have a higher risk of carrying genes associated with beta-thalassaemia.

The focus will now turn to the emergence of South Asian communities in Britain including their health and socio-economic profiles.

### **2.3.1 The history of South Asian immigration**

Although the main wave of immigration occurred in the years following the Second World War as a direct response to the severe labour shortages, immigration from what was India had occurred from an earlier period. Initially, Indians came to the UK in the guise of servants and nannies returning with families employed by the East India Company in and around the 1600s (Visram, 2002), or as seamen awaiting re-employment and thus clustering in small settlements around various ports (Ballard, 1994). These early manual and domestic immigrants were replaced by professionals and students during the nineteenth century. Many came on scholarships to obtain professional qualifications, thereby enabling them to gain entry into the structures of

colonial hierarchy back home. However, some stayed on to practice their professions in the UK after having qualified (Visram, 2002).

The post World War II boom saw the emergence of increasingly large scale and capital-intensive industries such as the motor industry which, in turn, required skilled and semi-skilled workers. Increasingly, British workers had unprecedented access to avenues of upward mobility facilitated by movement into the newer occupations, leaving a residue of unskilled, 'dirty' and labour intensive jobs at the lower end of the market including the NHS. To help fill these positions, British Government ministers, including Enoch Powell, undertook a recruitment drive in Commonwealth countries. Aided by citizenship status to migrants exempting them from the provisions of the 1905 Aliens Act, Commonwealth citizens were thus granted special immigration status. The British Nationality Act of 1948 conferred on them the right to freely enter, work and settle with their families. As a result, throughout the 1950s and 1960s, increasing numbers of Commonwealth migrants began to arrive, first from the Caribbean, parts of Africa and the Far East. By this time, India had fragmented to form East and West Pakistan as well as the main Indian landmass. East Pakistan subsequently became Bangladesh after its war of independence in 1971 (Mason, 1995) as illustrated in figure 6 which gives a visual illustration of the Indian subcontinent in the present day:

**Figure 6: Map of the Indian Sub-Continent**

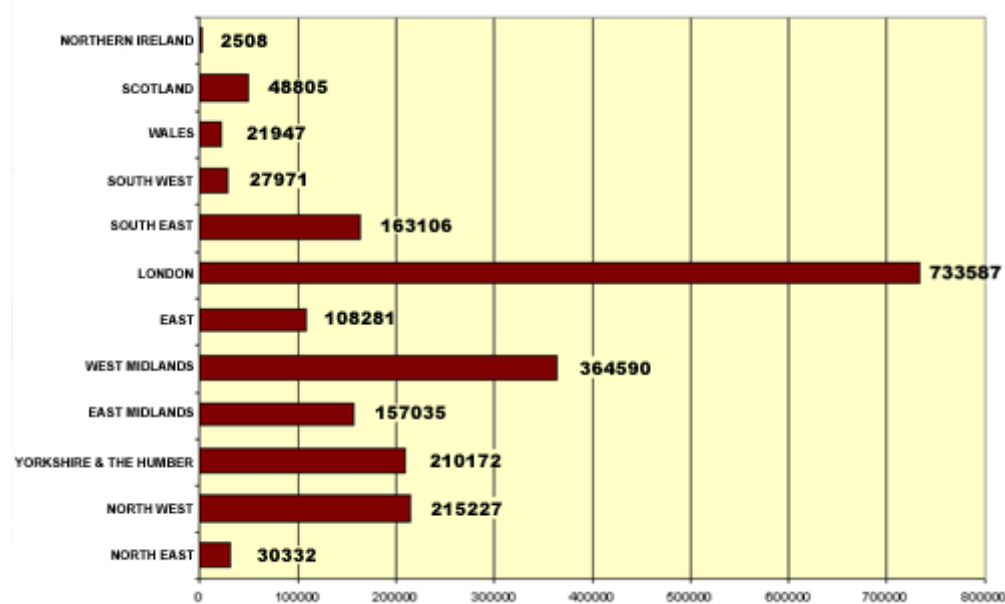


Source: Taken from <http://www.travelguidereference.com/country/countries.ehtml?o=8> [accessed 17 November 1010]

The next significant wave of immigration occurred during the 1960s and 1970s, when large numbers of East African Asians entered the UK after they were expelled from Kenya, Uganda and Zanzibar. Subsequent to this influx, the Immigration Act 1971 restricted any further primary immigration, although dependants of established migrants were permitted to join them. This has resulted in the formation of communities who, although having their ethnic origins in a geographically specific area (the Indian sub-continent), are also diverse in nature. It is estimated that one in four Indians and Pakistanis in Britain had arrived via East Africa and were mainly Gujaratis who entered the small and medium business sector as well as the medical professions (Ballard, 1994).

The early settlers gathered around urban areas such as the Midlands, Lancashire and Yorkshire, as well as the major population centres of London and Birmingham (Phillips, 1998), where many of them entered the transport industries, heavy and electronic industries as well as occupations linked to the textile trade. These patterns of settlement not only reflected the types of employment available to early migrants upon their arrival in Britain, but they were also indicative of the way in which new immigrants tended to cluster around areas in which there were people from similar backgrounds, kin perhaps who helped them to gain employment in their own sectors (Simpson, 2004). Figure 7 illustrates in more detail the geographical distribution of South Asian communities in Britain.

**Figure 7: Regional distribution of South Asian communities in the UK**



Source: Image courtesy of <http://www.historytalking.com/BLFolder/blpolupation.htm> [accessed 17 November 2010]

The general assumption that migration was a direct result of poverty is erroneous. Migrants represented all social and economic classes as well as levels of education. A large number were in craft industries, while others were students or in professions such as medicine and saw migration as career advancement. Many South Asians came from farming backgrounds from the agricultural districts of India and Pakistan and were attracted by financial advancement; this was not a means of primary income, but of supplementary incomes to buy additional land or to be used in familial marriages (Ballard, 1994). Indeed, in the early period, many such immigrants viewed their stay here as a temporary transition and had come with the sole purpose of financially securing their futures and then returning home (Anwar, 1979). Certainly, this would account for much of the material deprivation that such families faced as the responsibility to send remittances outweighed the need for material accomplishment here. Bhachu (1985) has suggested that the emphasis given to returning home has impacted upon these groups, especially Bangladeshi and Pakistani, to the extent that the repercussions of *“minimisation or prevention of contact with the wider society”* (p4) are still being felt today in terms of the impact of social exclusion.

In addition to the geographical and cultural diversities of the South Asian population, their experiences in Britain are also characterised by marked socio-economic differences and this is the focus of the next section.

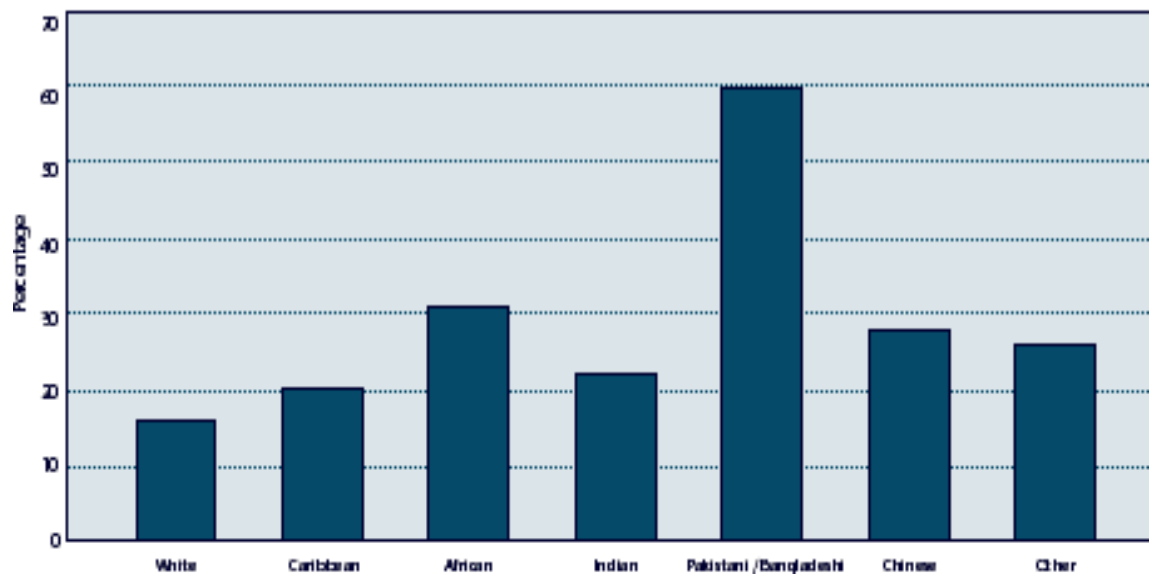
### **2.3.2 The economic profile of South Asians**

There are ample data to suggest that most ethnic minority groups are disadvantaged in some form or another compared to the majority white population. Anwar highlighted that the vast majority of migrants from Pakistan and the former East Pakistan came from rural areas where the general standard of living and education was very poor (Anwar, 1979). This scenario seems to have continued in the present day, a situation highlighted by the Joseph Rowntree Foundation report, which illustrates the discrepancies *within* the South Asian communities in terms of deprivation, whereby Pakistanis and Bangladeshis consistently suffer the greatest disadvantage in socio-economic terms (Nazroo, 1997; Platt, 2006).

Although the migratory factor may be regarded as a contributory cause for their continuing socio-economic problems, it has also been argued that much of the material, social and psychological disadvantage faced by the ethnic minorities is structured around their geographical locations. For instance, 60% of ethnic minorities live in inner urban areas in London, West Yorkshire and the West Midlands, where only 18% of the total white population reside (Nazroo, 1997). Berthoud (1998), in his analysis of deprivation in Pakistani and Bangladeshi households, showed that these particular populations were almost four times as likely to be 'poor' as white households. This finding is graphically represented in figure 8.



**Figure 8: Proportion of households living below an average income**



Source: Taken from Berthoud (1998:2)

The housing stock has also been considered a major issue in that, although the level of owner-occupied homes has been high especially among Indian and Pakistani populations (Tomlins, 1999), the quality and standard of these homes have generally been lower relative to the ethnic majority population. Indeed, earlier studies had noted the lack of basic amenities in South Asian households such as telephones and central heating (Anwar, 1996). Poor living conditions such as the ones highlighted can have a detrimental effect on families living with chronic conditions, such as  $\beta$ TM (Lundy & Janes, 2009). Not only are they members of a marginalised minority ethnic population but they also live in poverty with inadequate living standards while managing a chronic illness such as  $\beta$ TM.

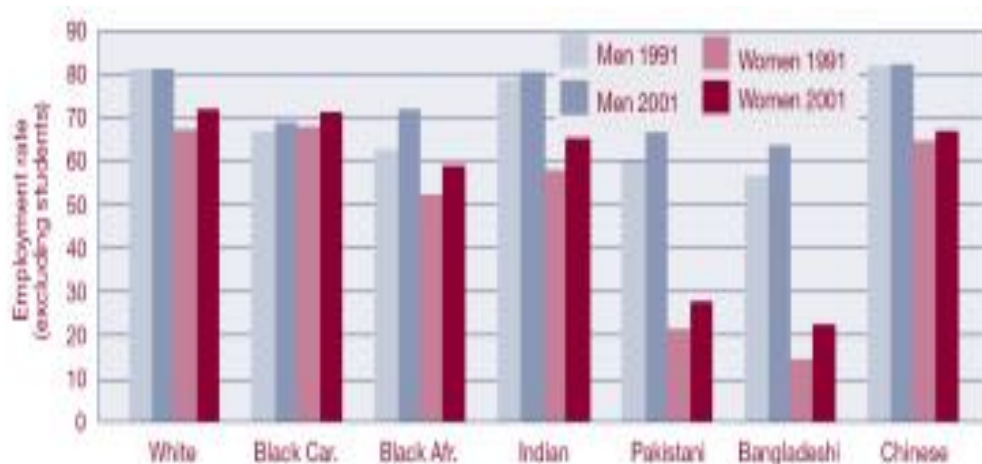
Figure 8 also highlights the socio-economic disparities within South Asian groups. For example, Indians have generally fared better and have carved out a distinct niche for themselves in certain areas of the economy in which they have made a significant contribution. For instance, the Indian population owns just over 50 per cent of the 'cash and carry' trade and just over 55 per cent of the independent retail trade. A large number began their careers in small corner shops or manufacturing industries (Parekh, 1997). In contrast, many Pakistani immigrants began working in labour-intensive industries and thus their pattern of migration and settlement closely matched the opportunities in the labour market such as Greater London, where they entered the service industries such as transport. Others settled in areas such as Manchester, Bradford and Birmingham where they were employed in the textile industries (Anwar, 1979). They continued to face major disadvantage in that they were more likely to be found in lower occupational grades, have poor job security and endure more unsociable work conditions as well as race discrimination and racism (Skellington, 1996).

South Asians, specifically those from an Indian background, have made significant contributions in professions such as medicine and more recently, new professionals entering the UK include IT professionals (at least two-thirds of whom are entering Britain from India) and workers in the hospitality industry who come from various states of India (Khadria, 2001).

Figure 9 is taken from a Joseph Rowntree Foundation *Findings* report into the state of the labour market (Clark & Drinkwater, 1997) and illustrates the employment status of different groups within the South Asian population. Although figure 9 shows that the

employment rates of both Pakistanis and Bangladeshis have improved over the last decade, they are nevertheless continuously underemployed compared to other ethnic groups including Indians. This is especially applicable to Bangladeshi and Pakistani women who have the highest levels of economic inactivity (at least defined by paid employment in the formal labour market). According to the Office for National Statistics, 75% of working-age Bangladeshi women and 69% of working-age Pakistani women were neither working nor seeking work in 2004 (cited in Babb *et al.*, 2006).

**Figure 9: Employment by ethnic group**



Source: Clarke and Drinkwater, 1997

While this may be due to a cultural emphasis on domestic and childcare responsibilities, lower educational attainment may also be a factor in that women with chronically ill children may not be in a position to pay for childcare, even with paid employment outside the home due to the poor employment opportunities available for women with low levels of education (Lindley *et al.*, 2006).

Nevertheless, women of Indian, Pakistani and Bangladeshi origins are beginning to make positive strides that will no doubt begin to impact upon the future rates of poverty and deprivation. This is reflected in recent evidence which suggests a gradual but consistent improvement in both educational attainment and economic progress (Hussain & Bagguley, 2007).

## **2.4 The health profile of South Asians**

The majority of studies conducted on health in relation to South Asian communities have tended to be epidemiological in nature. Although such research is important in ascertaining the health of ethnic minority groups and planning appropriate health services, it makes the all too common mistake of not recognising health inequalities *between and within* ethnic groups. For example, although South Asian populations have been shown to have a higher incidence of cardiovascular disease (Wild *et al.*, 2007), Indians tend to have a lower risk factor (Bhopal, 2000b) which may in part be due to having more affluence than the Pakistanis and Bangladeshis (Dyson & Smaje, 2001). Explanations as to the underlying cause of cardiovascular disease have tended to focus on the impact of racism and socio-economic deprivation (Karlsen & Nazroo, 2002; Williams *et al.*, 2010). In addition, lifestyles, biological tendencies such as the ‘thrifty gene’ (Sniderman *et al.*, 2007) and the effects of the migratory process have led to different health experiences and outcomes among South Asian communities, especially for males (Tillin *et al.*, 2008).

In contrast to the more affluent Indians who came to Britain to fill better paid professional jobs or who took up self-employment, others such as the Pakistanis and Bengalis fared relatively worse in labour-intensive and poorly paid industries with little support (Phizacklea & Wolkowitz, 1995). These environments resulted in an amalgamation of poor health, education, communication skills and racism, which have prolonged the effects of socio-economic and health deprivation in an otherwise healthy migratory population that is still being felt today (Dyson & Smaje, 2001).

In addition to cardiovascular disease, the related issue of diabetes remains very much in the public domain. Research shows that the prevalence of diagnosed non-insulin dependent diabetes among South Asians is over five times greater than that among the majority white population (Modood *et al.*, 1997). This has resulted in 20 per cent of people of South Asian origin over the age of 40 having this condition (Barnett *et al.*, 2006), and it is an added risk factor for a variety of other diseases such as renal failure (Nazroo, 1997).

High infant mortality rates among children of Pakistani-born mothers are areas of concern. Annandale (2003) highlighted the infant mortality rate as being 16.6%, which may reflect the higher deprivation and inequality of access to health suffered by Pakistani mothers and their children in Britain. This was confirmed in a much more recent study which suggested that the mortality rate among babies born of Pakistani mothers was twice as high as those in the white majority population (Office for National Statistics, 2006).

While heart disease and diabetes are known to have a very high prevalence among South Asian communities, other illnesses considered commonplace among the white majority population (e.g. cancer), are increasing within the South Asian diaspora. For example, the assimilation of Western lifestyles as a result of factors such as acculturation, are changing the risk factor for diseases such as cancer, which have traditionally been low for South Asian groups. The incidences of cancers such as breast and lung cancer, although lower than the majority White population, are rising, as are those of oral cancer particularly among South Asian men arising as a result of cultural practices such as chewing tobacco (Pau *et al.*, 2003). Additionally, while these cancer rates are lower than the majority English population, they are, nevertheless, rising and are higher than those in the Indian subcontinent (Velikova *et al.*, 2004).

#### **2.4.1 Access to and uptake of health services**

In addition to the diverse socio-economic disadvantages and ill health, there has been considerable interest in the ways that patients from BME backgrounds access and utilise healthcare services in comparison with white patients. Many studies have found that poor access to health services is a result of poor communication, perceived or experienced racism, or services that are deemed to be culturally or religiously inappropriate or inaccessible (David & Kendrick, 2004; Goddard & Smith, 2001; Smaje & LeGrand, 1997; Szczepura, 2005), leading to a general consensus that equitable care is not equitable or accessible to patients from minority or marginalised backgrounds and which is contributing towards their poorer health and disease management. In addition, many minority ethnic populations tend to be registered with GPs who are located in

deprived inner city areas, where they are usually single handed managed practices with access to fewer resources and training (Nazroo, 1997). As will be shown in later chapters, GPs are often unaware of the prevalence of the  $\beta$ TT in South Asian communities and they feel under qualified to discuss hereditary information on genetic disease (Qureshi *et al.*, 2006), factors which impact upon the process of screening, communication and informed decision-making in patients at risk of producing children with  $\beta$ TM.

Issues about service access and uptake are not only pertinent to those who are current service users but are of even greater importance for the planning of services to meet the needs of future health and social service customers. Although a vast proportion of the Pakistani and Bangladeshi populations is still young - 38% of Bangladeshis and 35% of Pakistanis are under the age of 16 (Office for National Statistics, 2004), many within these communities report ill health at a younger age than the majority white population (Randhawa, 2007). This will necessitate the need for focused attention towards providing appropriately targeted services such as the management of long term chronic illnesses for both sufferers as well as carers, who may themselves be in poor health.

In addition to health, family size will also warrant consideration for future policy planning. Rees and Butt (2004) by examining the differing patterns of population growth within South Asian communities, have illustrated that despite Indians being the largest ethnic minority in the UK, they have a slower rate of growth compared to Bangladeshi populations and a slightly slower growth than Pakistanis. Lindley *et al* (2006) have suggested that 5% of Pakistani women have larger than average families

comprising four children. This will have an added impact upon the delivery of reproductive services, for example, and the need to become aware of the increased potential need for services such as genetic counselling and screening, especially to the higher risk Pakistani populations.

## **2.5 The current socio-political situation**

The experience of health services and related issues of perceived bias, lack of access and communication cannot be discussed without giving consideration to the current political climate that many South Asians, especially Muslims, find themselves in. The post 9/11 and 7/7 climates have led to many Muslims being subjected to the public gaze and under constant scrutiny. This may be due to negative media exposure where, in many cases, the dominant narrative has been one of Muslims posing a threat to the British way of life and British freedom (Richardson, 2007), or it may be due to Government initiatives such as the re-invigoration of ‘stop and search powers’ and anti-terror legislation (Pantazis & Pemberton, 2009). This will no doubt impact upon the perception of service accessibility and the extent to which provision is perceived as being delivered in a non-biased manner.

## **2.6 Conclusion**

This chapter has highlighted many factors which impact upon South Asian populations and their socio-economic and health experiences, and which may have ultimately resulted in their marginalisation. In the context of the current study, prevailing disquiet about the impact of health and social welfare issues provide the focus for more



immediate health concerns of South Asian women, whereby they may relegate ‘hypothetical issues’ about hereditary conditions (such as the  $\beta$ TT) until these disorders become visible (e.g. have a  $\beta$ TM child). Furthermore, the systematic delivery of inequitable healthcare may be more acutely felt by minority ethnic populations such as South Asian women, as they experience services such as antenatal screening, prenatal diagnosis and services for families affected by long term chronic illnesses such as  $\beta$ TM. The marginalisation of South Asian women within the context of health and social service provision is further underscored by issues of culture, ethnicity and religious factors and will be discussed in more detail in forthcoming chapters.

## **CHAPTER THREE: LITERATURE OVERVIEW**

### **3.1 Introduction**

Chapter one introduced the study by providing a clinical, epidemiological and socio-political overview of beta-thalassaemia. Chapter two provided an in-depth discussion of the South Asian population and examined their socio-economic and health profiles in addition to the issues in accessing health care within this present day socio-political context. This chapter will provide an overview of the literature on health care, social and political manifestations of beta-thalassaemia, lay beliefs of illness and the politics of gender reproduction within the socio-cultural and religious context.

There is some debate within grounded theory about the appropriate time in which to undertake a literature review. Some theorists, for example, Glaser (1978) have argued that it should be conducted after data collection to avoid shaping the data analysis to conform to already known concepts and theories (Schreiber, 2001). Others (Strauss & Corbin, 1990) have argued for the novice researcher to acquaint themselves with the literature prior to data collection. Due to the fact that beta-thalassaemia and the issues surrounding it were a relatively new subject areas for me, I decided to conduct a literature review prior to data collection in order to both familiarise myself with the topic as well as to inform the interview schedule. Subsequent to this, literature was accessed and reviewed at regular intervals throughout the study in order to remain up to date with current ideas and themes, as well as to inform analysis and discussion.

The literature review for this study was facilitated by the utilisation of various search engines and databases such as <http://scholar.google.co.uk>, Medline, OVID, ASSIA, Web of Knowledge and [www.ingentaconnect.com](http://www.ingentaconnect.com). Key search words such as 'beta-thalassaemia', 'thalassaemia major', 'genetic screening', 'attitudes/experiences of South Asian women', 'meanings of illness', 'culture and illness', 'chronic illness', 'lay beliefs in medicine', 'women and illness', 'gender reproduction', 'global prevention', 'managing chronic illness', 'illness and identity', 'social models of disability' and so on were used to conduct these literature searches. In addition, names of researchers known to be experts in the relevant fields were also used to conduct database searches such as 'Ahmad', 'Ahmed (Shuhaib and Shenaz)', 'Atkin', 'Anionwu', 'Dyson', 'Green', 'Marteau', 'Daar', 'Modell', 'Petrou', 'Nazroo', 'Shaw' and 'Hewison'. References highlighted were non date specific and were based on the relevance of the literature to the research topic, but efforts were made to keep within the last 15-20 years to include documents that initiated policy changes in the diagnosis, management and service delivery of beta-thalassaemia.

The majority of studies that will be discussed in this chapter are multidisciplinary, employing, for the most part, qualitative research methodologies to explore in-depth socio-cultural meanings, experiences and understandings of stigma, illness, genetic information and chronic illness. This reflected the qualitative approach adopted in this study, which examined the experience of  $\beta$ TT among South Asian women within the context of haemoglobinopathy policy development, stigma, meanings and the

management of illness and genetic information as well as the social, familial and cultural impact of  $\beta$ TT on participants.

### **3.2 The medical and lay perspectives of illness and the beta-thalassaemia trait**

Historically, there has been a clash in the models developed for understanding the physical states of the body. The biomedical system on which Western medicine is based has often been criticised as being dualist and reductionist (Locke & Gordon, 1998) which according to Wade and Halligan (2004:1398), *"stems partly from three assumptions: all illness has a single underlying cause, disease (pathology) is always the single cause, and removal or attenuation of the disease will result in a return to health"*. There is a growing recognition that the reductionist assumptions are narrowly defined and mechanistically flawed, ignoring or neglecting the social and psychological issues that may impact a patient either directly or indirectly. Freidson (1984:223) highlights this division when he states that:

*"While illness as a bio-physical state exists independently of human knowledge and evaluation; illness as a social state is created and shaped by human knowledge and evaluation."*

In order to better overcome these deficiencies in understanding the dynamics of illness, there have been movements towards more contextualized models in areas such as nursing, public health, psychology, sociology, and anthropology. One such model is the bio-cultural model, which challenges the assumptions made by the biomedical model and has its origins in fields such as medical anthropology. Encompassing the disciplines of cultural and biological anthropology, it examines the interconnection of

health, disease and healing through an evaluation of a number of factors including biology, environment, psychology, social organisation and political economy, often with the intention of improving health care delivery. People are accordingly seen as holistic beings with interrelated biological and socio-cultural contexts. In contrast to the individualistic nature of the biomedical system, the bio-cultural approach underscores the importance of collective responsibility. It is thus important to recognize that the study of disease or illness does not generally take place in a vacuum, but that diverse issues may impact it.

In addition, there is a growing body of empirical literature which suggests that people's reality or meaning of a physiological disorder, or of health and the perception of risk, are shaped by many variables. This may include patterns of belief prevalent in that society and attitudes conveyed by family and friends, which will then influence whether or how a person engages in health-promoting or treatment behaviours. These 'lay' perspectives on health and illness have, through sociological and anthropological constructs, contributed enormously to the general understanding of the actual experience of a wider array of diseases, for example, leprosy (Mischler, 1981), heart disease (Pollard *et al.*, 2003; Whincup *et al.*, 2002), diabetes (Lawton *et al.*, 2008b; Lawton *et al.*, 2008a), breast cancer (Avis *et al.*, 2005) and hypertension (Brown & Segal, 1996), to name a few. Such accounts have focused on issues such as the beliefs of cause of disease, perceived and experienced stigma, biological connotations, uncertainty and fear for present and future life as well as the varied attempts at renegotiating identities and constructing 'self' in the face of so many uncertainties

(Charmaz, 1991; Charmaz, 1994; Helman, 2007; Mathieson & Stam, 1995). Social scientists have also described the variety of lay concepts of what constitutes health and illness and the moral and personal implications of such beliefs in areas such as care-giving and help-seeking behaviours for illnesses such as mental illness and HIV testing (Lupton *et al.*, 1995).

Studies in the lay understandings of risk in genetics (Hallowell & Richards, 1997; Kerr *et al.*, 1998; Parsons & Atkinson, 1993) have argued that beliefs about hereditary disease are grounded in the social routines and practices of everyday life and that they tell us as much about family and friendship networks as they do about ‘objective’ medical evidence (Richards, 1997). Indeed, it could be argued that people do not simply absorb medical information but rather that they actively *use* it to make sense of their experiences as asserted by Kerr *et al.* (1998). The ‘problem’ is that people who carry a genetic trait inhabit a ‘twilight’ world in which they do not themselves have an illness, but rather, a condition which may have *potential* consequences for themselves as well as their future children. As such, whilst the trait certainly has a biological basis, and very few outward medical symptoms, it cannot be comprehended in medical terms alone without understanding the personal and socio-cultural contexts of derived meanings (Atkin *et al.*, 2008). It is in this context that I sought to identify the issues and understandings of the meanings of the  $\beta$ TT in relation to health and illness in the socio-cultural, personal and religious sense to provide a basis for further understanding its impact.

### 3.3 Thalassaemia and healthcare provision

Research into South Asian health has tended to be focused on areas such as epidemiology and the management and prevention of chronic long-term illnesses such as diabetes (Lawton et al., 2006; Patel & Bhopa, 2007; Whincup et al., 2002) and heart disease (Jones et al., 2008; Nazroo et al., 2007). Recent attention has been diverted to issues such as the effects of chewing tobacco and smoking (Rehman et al., 2003), obesity and its impact (Retnakaran et al., 2006; Sniderman et al., 2007) and the rising incidences of certain cancers (van Laar et al., 2010; Velikova et al., 2004; Winter et al., 1999).

Although research in the UK into the prevention and clinical management of hereditary disorders has primarily focused on aspects of cystic fibrosis, Huntingdon's disease and Tay-Sachs, recognition of service provision needs in genetic disorders such as sickle cell disease and thalassaemia was recognised as far back as 1993 and incorporated into the recommendations of the Standing Medical Advisory Committee (Standing Medical Advisory Committee, 1994). However, these recommendations were neither funded nor mandatory and, as such, there was little progress in the provision of equitable genetic services, a finding recognised by Hogg and Modell (1998:1) who reiterated that haemoglobinopathy services were *'falling below the standards recommended'*. Other researchers went on to suggest that, because haemoglobin services were not prioritised by health and local authorities, they had not been adequately developed (Anionwu & Atkin, 2001; Dyson *et al.*, 1993a; Prashar, 1985; Streetly *et al.*, 1997). Haemoglobin disorders were viewed as 'exotic' and therefore racialised, which resulted in their

marginalisation from mainstream services (Ahmad & Atkin, 1996; Anionwu & Atkin, 2001). The 'it doesn't affect us' attitude, especially with regard to conditions perceived as exotic, is then exacerbated by language difficulties and cultural differences, which may lead to disparities in the health care experience of both BME patients and health care professionals (Pellatt, 2007).

Subsequent research took divergent views as to the route haemoglobinopathy services should take within the genetic health services agenda. According to Dyson (2005), multi-ethnic counselling attempted to amalgamate sickle cell and thalassaemia with other genetic disorders such as cystic fibrosis, Huntingdon's disease and Tay-Sachs (Anionwu & Atkin, 2001). However, the disadvantage of that approach was that the distinct issues and service and clinical needs of sickle cell and thalassaemia are ignored (Anionwu & Atkin, 2001).

### **3.4 The impact of beta-thalassaemia major**

There seems to be conflicting thought as to what living with a haemoglobinopathy such as  $\beta$ TM may actually mean. Certain writers such as Thompson *et al* (1994) have suggested that those living with such a haemoglobinopathy oscillate between the disabled and chronic illness experience. Indeed, the medicalisation of  $\beta$ TM or the trait has resulted in an over-emphasis on the clinical aspects of these conditions and their potential impact upon quality of life, reproduction and the economic and social burden of these illnesses. The medical model of disability which views the person with a chronic illness or disability, such as  $\beta$ TM, as the problem, suggests that he or she should



endeavour to normalise and fit into society (Bury, 2002). Others such as Begum (1994) suggest that the social model of the disability narrative should be the more dominant as most problems associated with either sickle cell or  $\beta$ TM are socially constructed; that is, those affected are not only limited by their own disabilities but also by the barriers that exist in society that neglect to take account of their needs. These barriers may encompass the physical, organisational or personal aspects of society and thus engender discrimination against affected people. Such discrimination in terms of South Asian cultures may be manifested especially in times of adolescence, marriage and reproduction (Hussain, 2005). Therefore, depending on the reader's point of view, the (medical and/or social) issues of people living with a haemoglobinopathy are comparable to those suffering from any disability or chronic illness and, as such, they have the same need for the active mobilisation of social, cultural or material resources to manage the illness (Beresford, 1996).

Compliance with medical treatment has enabled children with  $\beta$ TM to survive well into adulthood and in turn have families of their own (Di Palma *et al.*, 1998). This longevity in turn, has an impact on quality of life issues. Research conducted on the management of  $\beta$ TM by children and adolescents show that there are major issues in how they manage their  $\beta$ TM. Atkin and Ahmad (2000b) discuss how compliance to chelation therapy encompasses both practical and emotional difficulties, as does the affected young person's sense of self and social image and their illness. Within this dynamic, the young person has to reconcile the consequences of non-compliance within the broader experience and responsibilities of 'growing-up' and maintaining a positive

self-identity in the face of perceived social stigma and discrimination (Goffman, 1963). Studies into psychosocial issues faced by children with  $\beta$ TM have discussed the body image which affected children have in comparison to non-affected children (Georganda, 1990) especially during more salient times such as adolescence. The stigmatisation of a person with  $\beta$ TM as weak and inferior can have potentially devastating consequences, as shown in a recent study Ghanizadeh et al (2006). Conducting a survey of 110 subjects with thalassaemia major using a quantitative measure, as well as face to face interviews, they found that approximately 49% had suffered from depression, 62.7% suffered from irritability and anger, more than 43% of the youngsters had recurrent thoughts of death and 27.3% had considered suicide. Whether these negative perceptions are inevitable in a long-term chronic illness or a result of disabling societal attitudes and barriers, which are exacerbated by a lack of appropriate support, is an important question but one that is not within the remit of the current study.

The impact on education is also a concern for children and their families in that frequent absence from classes is necessary in order to undergo transfusions (Khurana *et al.*, 2006) as is the impact of a restricted social life. Although the Indian children in Khurana et al's study initially indicated that  $\beta$ TM had not affected their social activities, it became clear upon further investigation that such children preferred the company of a smaller, closer circle of friends and had restricted their activities ((Khurana *et al.*, 2006). This could be viewed as a vindication of the social disability model in that the society in which these children were living had not made the necessary adjustments to enable them to engage in the usual activities of their peers.

Parents of chronically ill children with disorders such as  $\beta$ TM have their own personal issues to manage. These may include self-blame, guilt, frustration, anxiety (Anionwu & Atkin, 2001) as well as isolation and forms of stigma (Goffman, 1963). In addition, parents of affected children also have to learn to negotiate social services and home care services (Atkin & Ahmad, 2000a). Issues of isolation can become exacerbated for South Asian women (both as mothers and patients), for example due to the misconceptions of health personnel who adopt the stereotypical assumption of South Asian women as religiously and culturally restricted (Burr, 2002) and, thereby assume that it would be futile to encourage attendance at any support groups that may be available. In addition, the view held by many health care providers that South Asian families have domestic support systems can be rather presumptuous since it neglects to recognise inter-familial conflicts and tensions such as those that can occur within multi-generational households (Chamba *et al.*, 1999; Chamba *et al.*, 1998). If the argument by Atkin and Ahmad (2000a) and Anthony *et al.* (2003) is held to be true; that is, that a parent's ability to cope with their child's illness is fundamentally influenced by material resources, family support and information about illness and its management, then one might surmise that parents living in the UK, for example, may be better placed to cope with chronic illnesses such as  $\beta$ TM, at least on an economically comparative level, than those parents 'back home' in the Indian sub-continent. While this may hold true in certain contexts, such as the availability of free health care and health benefits for carers in the UK, the financial costs of raising a disabled child are not insignificant. This can be exacerbated in households that suffer socio-economic deprivation such as South Asians of Pakistani and Bangladeshi origin (Clark & Drinkwater, 1997). Such

families are, for a variety of reasons, less likely to receive their full social security and social care entitlements, although a growing number of families, with the help of advocacy, have qualified for aid in the form of discretionary community care grants, which have helped to alleviate some financial difficulties (Hingorani, 1991). In addition to the financial and material hardships, Darr (1990) found in her study that families also tended to be isolated in that they thought their child alone suffered from  $\beta$ TM. Isolation can also be exacerbated in the South Asian diaspora, where extended family and kin networks are not as extensive or they are more geographically fragmented than may be the case 'back home'.

Findings by various authors have indicated that  $\beta$ TM has an especially negative impact on the quality of life of a mother with an affected child (Caro *et al.*, 2002; Goldbeck, 2001; Zahed *et al.*, 2002). Regardless of which model one may choose to contextualise these issues, families in certain circumstances do face additional emotional issues as well as isolation and financial pressures. Although parents of affected children may be confronted with emotions such as frustration, guilt, anxiety and helplessness in watching their child suffer (Anionwu and Atkin, 2001); they nevertheless seek coping strategies to manage the potential dangers of the disease. For example, Hill (1994) reported that some mothers of children with sickle cell disease only partially embraced the biomedical model as a way of coping, a finding also echoed by Atkin and Ahmad (2000a:59), who identified responses such as 'engulfment' and 'balancing/boundary setting' that were employed by parents in order to manage their child's illness. Similarly, in Hill's (1994:155) study, mothers or parents constructed their own

meanings of their child's illness in relation to their "*resources and values, and meanings*". Partially embracing the medical model enabled not only the understanding of the illness but also, by virtue of treatment regimes, allowed for the development of routines, the security of which was important in parent's coping mechanisms (Atkin and Ahmad, 2000a).

Due to the routine interventions associated with the treatment of  $\beta$ TM, such as transfusions and chelation, the medical model constitutes a sizeable element of the chronic illness experience. Even then, it is nevertheless only part of the coping strategy. Normalisation is also used in order to enable the child to live according to societal and cultural norms (Schur *et al.*, 1999). Studies of families facing diverse chronic illness issues have consistently found that, in due course, family members come to view both their affected child and their own lives as normal. Homer et al (1998) have described families of children with asthma as demonstrating a parenting style of normalisation, while May (1997:18), in her study of low birth weight infants, described searching for normalcy as the process through which mothers achieved a "*family lifestyle not centred on infant vulnerability, care giving, and caregiver burden*". Endeavouring to normalise the experience of chronic illness is also used by both parents and those affected as a strategy to overcome social stigma since this has the potential of leading to a 'spoiled identity' (Millen & Walker, 2000). Deatrick et al (1999) suggest that, while families recognise the seriousness of the illness, they continue to view their child and family as unchanged, which then sets the stage for managing illness-related demands in a way that sustains usual socio-cultural patterns of family and child functioning. These

attempts at attaining normalcy are interlinked with the negotiation of identities, as illustrated by Atkin et al (2002) in their study of young South Asian deaf people and their families. The young people attempted to gain some normalcy by managing their potentially stigmatised identities, albeit against a backdrop of ethnicity, religion, gender, racism and deafness. Their parents, on the other hand, normalised their child's deafness by focusing on behaviours and attributes that would reflect a cultural ideal such as a good education, social skills, knowledge of parental religions and cultures, and assuming adult roles such as having a job and being married. Based on these findings and of importance in the current study, the women (and their families) who have a thalassaemia major child may also adopt similar normalising behaviours with regard to their children to avoid stigmatisation within their communities (Goffman, 1963).

In addition to the psycho-social impact, much research has focused on physical aspects of living with  $\beta$ TM and the medical manifestations of the condition (for example, the possibility of organ failure through iron overload), which can exacerbate communication issues between parents and health care professionals (Atkin & Ahmad, 2000b). There has been much work conducted on the linguistic challenges facing organisations such as the NHS. A study by Szczepura *et al* (2008) found approximately 300 different regional and national languages being used in London alone which, in turn, led to issues about resources and the availability and utilisation of trained interpreters. Gerrish et al (2004) suggest that one possible reason for the lack of professional interpreter input in consultations (even in more recent times) may be the lack of awareness among patients of the availability of these interpretation services.

Service providers, in contrast, report lack of ready access to suitable culturally and linguistically qualified interpreters when they are most needed in general practitioner (GP) surgeries and hospitals for example. As a result, in order to avoid having to reschedule appointments or delay ward rounds, frontline staff will frequently make use of family members as a convenient alternative to accredited interpreters. However, using family members as interpreters can lead to potential problems since they are not neutral parties as they may have a personal or emotional interest in the situation (Herndon & Joyce, 2004). In addition, the role of the interpreter is to facilitate communication between the two parties in a professional and coherent manner (Tribe & Lane, 2009) and the use of a family member, or even a friend, can result in gatekeeping important information, especially 'bad news'. This can have knock-on implications for the consent process and, as a result, hamper patient-centred care (Howard & Marshall, 2009). It could be surmised, therefore, that in cases of genetic counselling for example, that the use of family or friends as interpreters may have even more negative consequences as potentially stigmatising issues such as hereditary traits and their implications for reproduction, are discussed.

Communication issues can also be exacerbated by negative stereotypic assumptions about South Asian women. Unsympathetic responses to their concerns by professionals have been reported in a number of studies (see Anionwu, 1983; Bowler, 1993a; Darr, 1990; Reynolds & Shams, 2005) which then led to feelings of anxiety, isolation, inadequacy and helplessness for the patients concerned and this, no doubt, will influence future uptake of services. In the context of the present research, the South

Asian mothers were asked about their experiences of the screening and subsequent counselling process and, in this way, the study sought to explore any concerns, anxieties or communication issues that the women may have experienced as a result of these encounters.

### **3.5 Women and illness**

The medicalisation of natural female processes such as menstruation, menopause and childbirth (Buckley, 1982; Riessman, 2002) has been resisted within the social sciences, which have attempted to place greater emphasis on experience of the condition. For example, Ballard et al (2001) showed that although women in their study incorporated the medical viewpoint of the menopause as a hormone deficiency disease in their discourse (McCrea, 1983), nevertheless they placed greater importance on the personal and social context in which the menopause was experienced. Medicalisation of women's bodies also has the potential to put women under greater pressure. Not only does it place them under the control of the medical professions but also consigns a responsibility for them to pro-actively protect themselves and their loved ones from illness and disease. This is especially evident during pregnancy when the female body comes under extensive medical scrutiny. The notion of risk places the onus on women to become 'moral pioneers' (Williams *et al.*, 2005) and have the moral obligation to ensure the health of their unborn babies. which is only realisable by the use of medical interventions such as ultrasounds and constant monitoring including ante-natal and pre-natal screening (Rapp, 1999).



This ethos of responsibility for either individual or familial health can also be extended to health promotion campaigns in which there is a presumption that once health risks are identified, individuals should take responsibility for their own and their family's health (Petersen & Lupton, 1996). This was confirmed by a study of lay expectations of the aetiology of illness which found that, although people regarded illness as having external causes, many accepted a limited degree of responsibility for their health and, as a result, the health of others (Pill & Stott, 1985). However the issue of 'locus of control' also needs to be considered when discussing South Asian women's health and responsibility since internal locus of control can arise from power, education and an understanding of health and illness, while for many South Asian women who do not have access to education or have no economic, cultural or social power, control is seen as external or in the hands of God or other outside influences, thereby absolving them of responsibility (Duffy *et al.*, 1997).

Atkin and Ahmad (1998) have discussed the stereotypic image among health care providers of South Asian women as passive and Muslim women especially as fatalistic. Perceptions such as these absolve health care professionals of any responsibility towards the proactive and culturally sensitive delivery of care which would ensure the health of both mother and unborn baby and their child or the prevention of the birth of a child with  $\beta$ TM. Therefore, there needs to be an appreciation that blanket stereotypes or labelling is unhelpful in that, as this study will show, the decisions that women undertook regarding managing their trait, screening and pregnancy management were made within diverse contextual situations in which they found themselves.

Gender inequalities in income and wealth make South Asian women especially vulnerable, even in the United Kingdom. Dhillon and MacArthur (2008) found that a familial preference towards the male child and multiple pregnancies led to a higher likelihood of depression. Gender inequalities in the Indian sub-continent, for example, result in overt discrimination against females in health, nutrition and general care which makes it difficult for them to acquire adequate provisions for health, especially during the reproductive years when family needs are greatest (Dhillon & MacArthur, 2008). Social norms about the divisions of labour and responsibility, especially in developing countries, mean that many women have very heavy burdens of work, in particular those who combine employment with domestic duties, pregnancy and child rearing (Doyal, 1995). To the extent that this is also true of women of South Asian origin, then, by the very nature of patriarchal society, women's health is subordinate to that of males' due to a variety of logistical, socio-economic and cultural reasons. For example, Shaikh et al (2008) suggested that women in Pakistan suffer due to a lack of appropriately qualified female health professionals as well as an unresponsive healthcare system which results in delays in seeking treatment or that they would, in the first instance, consult local faith healers due to cultural and economic reasons. While these experiences may have been reflective in the behaviours of first-generation women for example, the second generation may be better informed of healthcare and are perhaps more able to actively utilise available support, thereby putting more distance between the situation 'back home' and here in the UK. This present study, by examining the perspectives of a much varied sample in terms of age, ethnicity and length of time in the UK, for example, will

examine whether acculturation processes have shaped the South Asian women's acceptance and uptake of health services such as genetic screening.

With regard to the active management of health and potential health problems, Lupton et al (1995) examined perceptions of responsibility in HIV testing and found that most testing involved people who were not necessarily 'high risk' but those who felt that a clean bill of health was a significant sign of affection and commitment in a relationship. Consequently, these tests represented social meanings that were very different to the prevention of HIV originally intended by medical professionals - the very fact that these tests were used to engage in sexual behaviour with, perhaps, different partners may indeed contradict the medical view of the purpose of development of the test in the first place. In a similar vein, genetic tests which are typically assumed by healthcare professionals as a way of encouraging proactive management of genetic information may not be viewed in the same way by lay people. Instead, the concept of genetic risk has diverse meanings for women in terms of their reproductive roles and moral responsibility, and includes implications for the wider familial and kinship networks in terms of marriage, for example (Parsons and Atkinson, 1993). One of the most obvious examples of this is the breast cancer awareness campaigns. Although the genetic factor in breast cancer is well known, this does not absolve gene carriers of their responsibility. Indeed, Hallowell (1999) argued that, because genetic risk is perceived by lay people as part of that person's make-up, they have an increased responsibility to protect their own and their family's health. The assumption in health campaigns is that women should take a proactive stance towards breast cancer, for example, and 'do their

bit' in its prevention or in raising familial awareness. As a result, genetic technologies in cancer have greatly increased pressures on women rather than reduced them, and it is possible that this may also be the case with the  $\beta$ TT. Women, as an extension of their nurturing role, are not only assuming the responsibility for themselves but also their children and partner's health as well (Graham, 1984; Wyn *et al.*, 2001)

### 3.6 Meanings of illness

While women's experiences of the  $\beta$ TT and major form the central theme of this study, it is necessary to obtain an insight into how women perceive, contextualise and manage their own and their family's health. A person's reality or meaning of a physiological disorder, for example, is shaped by many variables such as patterns of beliefs prevalent in that society, the attitudes of friends and family, the notions of cause and effect and remedy of the disease and the fear of stigma (Goffman, 1963). Friedson (1984:223) highlights the point well when he states that:

*“while illness as a bio-physical state exists independently of human knowledge and evaluation, illness as a social state is created and shaped by human knowledge and evaluation”*

Discussions of illness typically include the physical manifestations of that illness. However, when a person is a carrier of a genetic trait, they tend to have an outwardly healthy appearance. That does not, however, negate any potential stigmatisation that these carriers may feel. For instance, although research on the illness experience shows that those who are ill often find themselves subjected to negative stereotypes and isolation (Crandall & Moriarty, 1995), there is growing literature also that shows that

these stereotypes are not confined to an illness that has physical manifestations (Gordon *et al.*, 2004; Savulescu & Kerin, 1999). Research by Sankar *et al* (2006) has shown that, in the case of illnesses which have hereditary manifestations, it is not the physical cause of the illness but the societal reaction to the illness which can cause stigmatisation. According to Goffman (1963), the fear of being stigmatised by one's friends, family and the wider community is one aspect of how a person will view and, consequently, disclose their status, for example as a carrier of a genetic trait. As the research participants in this study were carriers of the  $\beta$ TT and did not have any outward physical symptoms, it is relatively easy to conceal their carrier status from family and friends. In some instances, it is so well hidden that people even deny genetic knowledge of the disease for fear that being seen to possess technical knowledge would implicate them as being carriers (Dyson, 2000). In another study conducted by Dyson (2000), South Asian women who had tested positive for the trait failed to inform partners of their trait diagnosis. Indeed, it may be the fear of stigma that resulted in their failure to disclose the trait (Dyson, 2000). Some researchers have suggested that stigma may not be present in all situations. For example, Darr (1990) has argued that there is no stigma attached to being a carrier due to the practice of consanguineous marriages among the Pakistani community since, in such circumstances, blaming one's partner would also mean blaming one's own family. Yet, Darr (1990) did not discuss the effect on families in which carriers had non-consanguineous marriages as characteristic among many marriages within the Pakistani community (Hussain & Bittles, 1998). Furthermore, as her sample concentrated on Pakistanis, it cannot be assumed that her findings can be replicated across South Asian communities. By

contrast, the present study will illustrate that affected women are not always absolved of stigma and that stigmatisation was felt by women who had  $\beta$ TT children regardless of their religious beliefs, ethnic identities or marriage patterns, which tended to differ across the ethnic groups.

Modell *et al* (1997) have discussed at length the different politics, marriage and kinship patterns within South Asian communities and religions. The Indian Hindu marriage customs, for example, are labelled as patrilineal exogamy in which marriages are between unrelated families. In contrast to consanguineous marriages, it may be assumed that, since there is no prior kinship or relationships between these Hindu families, solidarity may be absent. Pakistani society, on the other hand, has been known to generally favour marriages from within the extended family system, thereby retaining familial ties and obligations (Modell *et al.*, 1997). However, although consanguinity is assumed to strengthen familial ties, the perceptions of consanguinity by ‘outsiders’, such as mainstream health care professionals, remains a bone of contention within the Pakistani community and will be discussed in depth within this study. Families in consanguineous marriages are constantly bombarded by the claims among health personnel that their child’s illness is a direct consequence of consanguinity (Ahmad, 1994; Kramer-Roy, 2007) which neglects to recognise that such parents witness other consanguineous marriages that are producing unaffected children as well as  $\beta$ TM children born from non-consanguineous unions.

This focus on consanguinity as a fundamental fact in poor birth outcomes has further implications for service provision. Ahmad (1994) and Bittles (2001), in questioning

the data relating to the birth outcomes of consanguineous marriages, have suggested that genetics alone cannot be held responsible for high rates of foetal disability. They argue that socio-economic factors and deprivation tend to be overlooked and should be considered alongside genetics in accounting for foetal abnormalities. This view is supported by Darr (2005) who argued that the Western emphasis on consanguinity has been an attempt to draw attention away from inadequate service provision and, as a result, to shift blame onto the families themselves. Further to Darr's work, this study will examine the perceptions and experiences of consanguinity among women who may or may not have a child with thalassaemia major, within a more geographically and socio-demographically varied sample.

The way any given culture and, as a consequence, any affected person reacts to an illness is partially determined by cultural norms (Kleinman & Benson, 2006). Parsons (1951) has defined illness as a form of deviance on the grounds that it disrupts the social system by inhibiting people's customary roles. Deviance in this context is taken to mean non-conformity to social values and norms that will make the ill person subject to sanctions. However, these definitions are more relevant to acute, short- term illness and neglect to take into account long- term chronic illnesses such as thalassaemia major, or even the impact of the trait as in the current study. Currer et al (1986), in their example of Pathan women suffering from depression, highlights this point. The women's 'illness' would only be deemed problematic if it restricted their cultural roles as mothers and wives and impacted on their daily responsibilities. Because it did not, the women's depression was not viewed as deviant regardless of the anguish it may have caused the

women in question. This is not to say that the symptoms of depression are not recognised in Pathan culture. Although the language is different, the translations of what constitutes depression in the West are not too different from that in Pathan society such as loss of appetite, insomnia or hypersomnia, for example. It can, therefore, be suggested that peoples' perceptions of illness and, indeed, outcomes of that illness are dependent on cultural values, social norms and personal and social narratives. In this case, the constructivist approach to the phenomenon of illness, whereby, interpretation derives from social meanings, social reality and beliefs, contrasts with the biomedical model since illness is defined as an objective reality (Mischler, 1981).

In another example, Nijhof (1995), in his study of people affected by Parkinson's disease, asserts that many of his research participants regarded having (Goffman, 1963). In addition, spoiled identity will also be examined within metaphors such as 'bad blood' (Chattopadhyay, 2006) will be used to explore the value of clean, untainted blood in terms of purity and lineage – both valuable reproductive assets.

In a similar example, Mischler et al (1981) have studied the effect leprosy has on its victims and their families. People living with leprosy suffer differing fates depending upon their area of residence or immediate community. Indian lepers faced a public backlash to the extent that they were forced to withdraw from society and from their families as leprosy was perceived as a punishment of some past sin and was therefore stigmatised (Waxler, 1981). In contrast, Sri Lankan Buddhists preach tolerance, compassion and mercy for those perceived as less fortunate (WHO, 1985) which would in part account for the lepers' treatment there. Religion also plays a fundamental role



in Pakistani society, whereby many believe that illness is the will of God – to test one's character and strength of faith.

Leprosy is an extreme example of the personal and cultural contexts of disease. More common ailments such as diabetes and heart disease have also been shown to have different contextual meanings within different cultures. Fitzpatrick *et al* (1984) have argued that people's ideas of illness change over time in relation to new information, circumstances and experiences rather comprising a stable or fixed set of beliefs. As such, negative meanings and perceptions of heart disease, diabetes and, more recently, drug use and HIV are slowly being overcome by the work of community outreach organisations such as Project Dil (Project Heart) in Leicester which aims to improve understandings of heart disease among the South Asian communities by training and utilising link workers employed from within these communities (The Department of Health, 2004a).

In the context of South Asian women's management of diabetes, Reed (2000) found that they drew on both cultural and Western influences. The women were as likely to try traditional remedies as Western ones to control their diabetes but, in some instances where the condition was very severe, Western medicine took precedence. Of relevance to the current study, women of South Asian origin may or may not apply traditional strategies such as hakims or alternative therapies to treat their status as carriers of the  $\beta$ TT or even to utilise traditional therapies to compliment a  $\beta$ TM child's clinical treatment protocol. Much would be dependent on their understandings of the

schematics of the genetic condition and what it means to be a carrier. It could also be that, in the case of a  $\beta$ TM child, Western medicine would take priority.

### **3.7 Genetics, reproduction and the South Asian woman**

The subject of genetics in South Asian women has been subject to close scrutiny in recent times. Much of the work conducted in this field has tended to focus on the screening process and the issues that arise in screening for South Asian women. It would be fair to suggest that medicine is an area that holds as many misconceptions as any other public field, including racist and religious stereotyping (Geiger, 2001). Historically,  $\beta$ TM has always been seen as a problem for Mediterranean communities, and concerted campaigns have reduced its global prevalence (Gill & Modell, 1998). The use of antenatal screening and termination of affected pregnancies has significantly reduced the number of thalassaemic births - by 96 per cent in Cyprus and 62 per cent in Italy (Kuliev *et al.*, 1992). Sardinia has seen a fall by 94 per cent (Cao *et al.*, 1998). Consequently, genetic screening before marriage or in early pregnancy has therefore become a way of life for people in those areas (Bozkurt, 2007). This can be contrasted to the South Asian experience in the UK in which it has been estimated that up to 78 per cent of newborn infants affected by  $\beta$ TM belong to these ethnic groups (United Kingdom Thalassaemia Society, 2005). The UK has seen the lowest fall in births of affected children – the majority of which are born to Pakistani mothers (Gill & Modell, 1998; Kuliev *et al.*, 1992). While public awareness campaigns have been promoted in the Indian subcontinent in more recent times, as this study will show, there is little to

suggest that knowledge ‘back home’ has permeated awareness in migrant communities in this country.

As discussed earlier, health care workers, including GPs, were not usually aware that people of South Asian descent were more at more risk of thalassaemia. The Royal College of Physicians of London’s (1989) enquiry into counselling for genetic disorders showed that, at that time, many areas with large South Asian populations had inadequate screening policies so that risk was either not identified or was identified too late in pregnancy for prenatal diagnosis and possible termination to be acceptable. While this was the situation in 1989, recent work has confirmed that the present situation is not too dissimilar. Many GPs still feel under qualified to discuss genetic traits and inheritance (Qureshi *et al.*, 2006). This may be resolved by the guidelines issued by organisations such as The UK Thalassaemia Society and The NHS Sickle Cell and Thalassaemia Screening Programmes, which highlight issues surrounding sickle cell and thalassaemia screening and clinical care. Research shows that South Asian women especially are subject to misconceptions and misrepresentations by health professionals. Asian women are accused of entering ‘the system’ too late for any adequate screening to be conducted (Atkin & Ahmad, 1998; Dormandy *et al.*, 2008). This claim, however, is refuted by haemoglobinopathy counsellors who insist that the GPs or ‘the system’ itself is responsible. In a recent study, Dormandy *et al* (2008) claimed that, due to the ‘booking visit’ occurring at twelve weeks gestation, it was difficult to meet with guidelines that suggested that screening processes should be carried out by 10 weeks gestation and prenatal screening by the end of 12 weeks

gestation. This study will therefore seek to establish whether women in this study have delayed their entry into the antenatal system or whether this is a misconception amongst health care professionals.

The area of antenatal care has recently come under closer scrutiny. Medicine in all its infinite wisdom assumes that “*people's behaviours comply with the current organisation of the health service*” (Calnan, 1987:1). This presumably means ‘following doctor's orders’. Practitioners in many cases have denied some parents prenatal testing due to stereotypical assumptions that termination would automatically be deemed unacceptable to women of South Asian descent (Atkin *et al.*, 1998). The diversity in opinions regarding this issue was illustrated by Darr (1990), who found that termination is acceptable to some Pakistani families and not to others, and is mainly refused due to the fact that the test is usually offered during the second trimester with the results being made available toward the end of the trimester - an issue of concern that is common across ethnic groups (Calnan, 1987:1). More recent work conducted on the attitudes towards testing and the management of pregnancy suggests that the decision-making process is governed not by religious beliefs alone, but is also related to attitudes towards termination which were generally within a more pragmatic framework (Ahmed *et al.*, 2008). Although decisions regarding prenatal testing were made in conjunction with family members or religious personnel (Bottorff *et al.*, 1998; Shaw, 2003), the conflict between values and beliefs was apparent among the majority of the South Asian participants in Ahmed *et al.*'s (2008) study which recruited across the major religions of the Indian subcontinent. Furthermore, in a study by Hirst *et al.* (2003), it was found that

67 per cent of Muslim families said that they would consider termination following a prenatal diagnosis of thalassaemia, despite the general assumption that Muslim populations demonstrate a greater reluctance to terminate pregnancies than other religious groups. These studies are useful in challenging misconceptions about the link between religion and termination among South Asian communities in Britain. In the context of the present study, the women's perceptions and experiences of prenatal screening and pregnancy were investigated and, in this way, the findings of the research may confirm or refute existing stereotypes.

The ideal of 'value free' genetic counselling (Clarke, 1991) has been contested by writers such as Williams *et al* (2002), who question whether it can actually be achieved in the real healthcare setting. Counsellors are accused of focusing on the negative aspects of the condition, which could be presumed as logical if one understands the rationale behind this. Genetic screening comes under the umbrella of the term 'New Genetics', the ethos of which is to identify 'at risk' couples, affected foetuses and newborn babies for haemoglobinopathies and to encourage parents to make an informed choice in reproductive decisions (Atkin and Ahmad, 1998). Since the concept of new genetics is integrated with the concept of health economics, the implicit ideal must be one of prevention (Michie *et al.*, 1998). Screening services were presented to health-care purchasers within economic analyses (see Zeuner *et al.*, 1999) that suggest that a significant amount of people will choose not to continue with an affected pregnancy and, therefore, it will be more cost effective for services to provide screening than provide lifelong care for a child suffering from an inherited genetic condition, where

there can be significant costs to the NHS. Hogg and Modell (1998:5), for example, have suggested the annual cost of treating a thalassaemic patient for 35 years life expectancy can be in the region of £280-350,000. The most up-to-date estimate suggests that this figure has risen to an estimated value of £803,002 (Karnon *et al.*, 1999).

Before the implementation of the NHS Sickle Cell and Thalassaemia Screening Programme, screening for such disorders in the United Kingdom was too *ad hoc* (Streetly, 2000) to be seen as a systematic implementation of the goal of cost-containment. In order to provide a blanket universal screening policy, the NHS Sickle Cell and Thalassaemia Screening Programme aimed to implement screening in high prevalence NHS Trusts by 2007 and in low prevalence NHS Trusts by 2008, thus establishing universal coverage in England. The NHS Sickle Cell and Thalassaemia Screening Programme has rolled out consent-based screening programmes in tandem with other initiatives, such as community outreach in collaboration with community groups and education programmes, which aim to increase awareness of haemoglobinopathies and universal screening as a way to educate communities and thus prevent affected births. There is significant evidence to suggest that information given or explained in a way that is incomprehensible to women has significant clinical and service-based implications, especially for those women who have issues with the English language and communication. This was confirmed in a study by Ahmed *et al* (2005), who found that the majority of women were not informed that routine antenatal screening can reveal the thalassaemia carrier status. Women who did not speak English

‘accepted’ this lack of information as they felt that it was not appropriate to question health care providers, as it may be perceived as a lack of confidence in service provision. In response, the NHS Screening Programme has attempted to overcome this deficit in informed consent by ensuring that women are required to give consent for antenatal tests, including sickle cell and thalassaemia screening.

It is widely understood that, in matters of reproduction, women act according to their own perceptions rather than accepting medical wisdom unquestioningly (Parsons & Atkinson, 1993). In the majority of cases, women face the burden of caring for thalassaemic children alone and they will manage an affected pregnancy according to their perceptions of being able to cope. For example, studies in Nigeria have shown that, although the status of motherhood has importance in the community, due to the burden of care being placed wholly on the shoulders of the woman and given that health care is inadequate, many women will chose to terminate an 'at risk' pregnancy rather than deliver an affected child (Durosinmi *et al.*, 1995). This view is in contrast to the work of Hill in the USA (1994) who argued that African-American mothers actively constructed their own meanings which rejected the medical (and thus by implication, negative) model of sickle cell disease and chose to continue with the pregnancies. Hill (1994) also highlighted the extent to which mothers relied on their own inherent perceptions rather than medical discourse with regard to their personal genetic risk and screening policies, possibly as a result of a history of mismanaged screening programmes by health authorities in the US. Parsons and Atkinson (1993) discovered that, rather than following medical advice as is hoped by health professionals, women

who had familial experience of Duchenne Muscular Dystrophy fell into three categories of risk-takers, risk-refusers or risk-modifiers. They concluded that risk-takers and risk-refusers (women who defined their risk as high regardless of the mathematical percentage) had different definitions of their situations. The risk-takers had a greater in-depth understanding of the risks than the risk-refusers, who had less desire for a child than the risk-takers. As with Hill (1994), Parsons and Atkinson found that lay perceptions of risk differed in terms of the meanings of the size of the risk to different participants and they concluded that motherhood was defined as an all-too-important status for women who fitted the categories of risk-takers and risk-modifiers that it was worth the potential risk of having a child with a genetic disorder. These findings have implications for this study in that it is important to understand how genetic risk is perceived by South Asian women since it has implications for the prevention of thalassaemia, the management of pregnancy and cultural practices (e.g. marriage). As a result, the present study will examine the perception of genetic risk and how it impacts the management of a pregnancy not only among Pakistani women who are at higher risk of having children with thalassaemia major but also among Indian and Bangladeshi women. It is these perceptions and experiences which, in turn, impact how the women will manage pregnancy and reproduction.

Despite being the most 'at risk' population for thalassaemia major, there is evidence to suggest that Pakistanis have a poor knowledge of thalassaemia (Gill & Modell, 1998). Historically, this view was mirrored by Dyson et al (1993c) who, by conducting quantitative research with 148 people in Manchester, ascertained that there were low



levels of awareness and knowledge about thalassaemia in communities which had a high prevalence of the condition.

Thalassaemia has not become part of the cultural repertoire of the South Asian community (Anionwu and Atkin, 2001) since, unlike countries such as Greece and Cyprus, the British South Asian communities have not been systematically and intensively targeted for an education and prevention programme. The NHS Sickle Cell and Thalassaemia Screening Programme has, in an attempt to reach at-risk populations, involved a community outreach component which attempts to redress issues of cultural knowledge and, in doing so, has the potential to enable a proactive stance in the prevention and management of a potentially stigmatising illness ( $\beta$ TM). Initiatives such as these, as highlighted by Fitzpatrick (1984) can eradicate negative perceptions and fear of an illness and lead to a better understanding of the dynamics, and thus the control of the disease, which has connotations of how  $\beta$ TM may then be considered in these populations.

Another important aspect in the case of this study is whether the socio-economic status of a person determines how women understand and use the information that is provided, which would in turn be influenced by education and acculturation. The present study was also interested in examining whether the meanings of the trait would be influenced by the social demographics and acculturation of the participants in this sample.

### 3.8 The international perspective

Initiatives in both developed and developing nations have focused on carrier testing of at-risk couples, including a focus on changing cultural practices. For instance, in Cyprus, Greece, Italy and the Islamic Republic of Iran, premarital screening for thalassaemia is standard practice and national audit data are available. Most at-risk couples are identified in sufficient time to be offered early diagnosis for the first pregnancy (Fucharoen & Winichagoon, 1997). This has led to the development of appropriate screening technologies and services in Bahrain, the Islamic Republic of Iran and Saudi Arabia. Increasingly, prevention programmes are being developed and introduced in many parts of South East Asia (Colah *et al.*, 2010). However, more recent work by Petrou (2010) in the context of couple screening in the Indian subcontinent has suggested that, even when couples are diagnosed as being at risk, they may go ahead with marriage despite the risk of giving birth to affected children. No doubt this is affected by the stigma attached to  $\beta$ TT and remaining unmarried in general.

Thalassaemia awareness and thus prevention programmes in the Indian subcontinent, and indeed in the majority of countries affected, have been led by private or charity hospitals that provide thalassaemia support as well as by local government and the media. In addition, organisations such as the Thalassaemia International Foundation have been assisting public education programmes via its international groups. The campaign to bring thalassaemia major under control has become focused on three fronts: to prevent consanguineous marriages and to undertake antenatal and prenatal screening in addition to encouraging the termination of affected pregnancies.

There has been much media coverage on initiatives led by various agencies to raise the awareness of thalassaemia. In Pakistan, where an estimated 5 per cent of the population carries the  $\beta$ TT resulting in approximately 5250 affected children being born annually (Ahmed *et al.*, 2000c) the Fatimid Foundation (a non-profit making organisation which provides blood and chelation therapy as well as advice on prevention of  $\beta$ TM) celebrated International Thalassaemia Day 2006 with a symposium attended by a special guest, the Senior Minister for Education and Training of the Government of Sindh Province, including patients, families and friends. The event attracted much media coverage as did similar events in India, the Middle East, Far East and Bangladesh.

Where initiatives to prevent the birth of  $\beta$ TM children have been implemented they have, on the whole, been met with positive acceptance. A thalassaemia screening programme in Iran initiated in 1996, which aimed to identify at-risk couples premaritally and to offer counselling, thus providing them with the opportunity to separate along the lines of the successfully initiated Mediterranean model (Bornik & Dowlatabadi, 2004). The premarital screening of 2.7 million couples over five years, followed by genetic counselling of more than 10,000 positive couples, has resulted in a 70 per cent reduction in the expected annual birth rate of affected infants in Iran (Samavat & Modell, 2004). With regard to developing nations, Iran seems to be the pioneer in its thalassaemia prevention programmes. In a recent evaluation of its first chorionic villus sampling programme, developed in parallel with fatwas issued by Islamic scholars who ruled on the permissibility and thus legality of termination, this

resulted in the acceptance and increased uptake of the procedure. For a low resource country this is a considerable achievement and, indeed, it has shown that such initiatives can be replicated in other such countries, in particular in Muslim countries. Perceived conservative nations such as Saudi Arabia have also taken on board the issue by passing a Royal Decree in 2003 for a mandatory premarital screening test followed by non-directive genetic counselling for haemoglobinopathies, thereby permitting the affected couple to decide whether to marry (Al-Gazali *et al.*, 2006). However, the next step of offering prenatal diagnosis and termination was unable to be implemented due to religious interpretation by various authorities, especially with regard to time limits in terminations (Al-Gazali *et al.*, 2006) and, as a result, proactive initiatives such as these are left incomplete and unsustainable.

Literature on the subject of thalassaemia from the Indian subcontinent has, in particular, tended to concentrate on the perceptions and politics of antenatal screening, including the potential of premarital testing to reduce affected births. However, Gosh *et al* (2002) have claimed that carrier testing and acting upon positive results would encounter problems in gaining acceptance in India due to the case that marriages are still largely arranged by the parents of prospective brides and bridegrooms. Hence, the very idea of communicating the carrier status to the bridegrooms' families may lead to cancellation of the marriage, and concealing the carrier status is associated with guilt both for the bride's parents as well as the bride. Another factor that may reduce the acceptability of such initiatives, especially in countries such as Pakistan, is the programme's attention to issues of consanguinity and changing cultural practices to avoid thalassaemic births.

Hafeez *et al* (2007) have suggested that the only way to eradicate thalassaemia major in Pakistan is to discourage consanguinity. However, if carriers do get married to each other, “*prenatal diagnosis should be done by CVS [chronic villius sampling] and termination of pregnancy is advised*” (p147). Not surprisingly, such approaches, which are seen to be a criticism of inherent cultural and religious values, may meet with a negative reaction. Of importance, the current study will examine whether initiatives such as premarital testing is perceived to be acceptable among British South Asian women (and their communities) as a means of avoiding carrier couples and possibly thalassaemia major children as this can have implications for current health policy and screening delivery.

### **3.9 Relevance to the study**

The review of the literature undertaken in this chapter suggests that the social meanings of the  $\beta$ TT are likely to be influenced by a range of socio-economic and contextual factors.

The evolution of haemoglobinopathy programmes and the universal screening policy in England have occurred in the context of underlying tensions of perceived and actual racism, demand and service needs for an issue that, until recently, was attributed as a problem for the ‘Exotic Other’. Although it has been shown that a screening policy is in place in Britain, there is a disparity in the time between presenting a pregnancy and the screening process which, in many cases, has been left too late for effective decision-making in an affected pregnancy (Dormandy *et al.*, 2008). Although some research has

shown that there is a diversity within South Asian communities with regard to the management of affected pregnancies (Ahmed *et al.*, 2008), there is little known about the dynamics of decision-making based on socio-economic differentiation or prior exposure to thalassaemia, as well as age and generation differences, namely whether younger participants would be more amenable towards termination of an affected pregnancy than older women. By maximising variation in the sample, I hope to ascertain whether socio-demographics and acculturation will impact upon the decision-making process in (affected) pregnancies.

Previous sections of this thesis have highlighted public (including health service) planning and delivery being influenced by both racism and racial stereotyping, which then impacted the inequality of access and uptake of these services for some sectors of South Asian communities. The current status of screening services in Britain, although improving, still has inherent problems with basic support services such as interpretation (Rudart, 1994). Although communication issues in genetic counselling (in areas such as cancer) are raised in the literature (Pieterse *et al.*, 2005), there is little indication about how South Asian women have understood the genetic counselling process and, in turn, disseminated the information to family and friends. The existing literature also overlooks how marginalised women such as South Asians, for example, make sense of genetic terminology and how it impacts the management of their pregnancies and dissemination to family and friends.

The socio-cultural emphasis on mothers as the main caregivers (Midence & Elander, 1994) has resulted in them carrying out the caregiving role while being unsupported. In

addition, researchers such as Crabtree (2007) have discussed how the birth of a disabled child brings shame and thus stigma to the Arab affected family. By extension of this argument, it could be assumed that mothers will be the focus of familial sanctions and stigma as a result of the act of giving birth to that child. Consequently, this study will aim towards a better understanding of the impact of a chronically disabled child upon the family and, indeed, marital relationships in the diaspora, within the context of female identities, motherhood and stigma.

With regard to the  $\beta$ TT, the literature has shown the socio-cultural and moral focus of health and genetics services on women in general and especially in areas of health and reproduction. There is little evidence to suggest how  $\beta$ TT would impact upon health, responsibility, gender and locus of control in proactive decision-making at particularly salient times such as adolescence, marriage and reproduction, especially when the fear of sanctions and stigma may be an overwhelming factor in the disclosure of a trait or 'discreditable attribute' (Goffman, 1963). Therefore, there needs to be an in-depth assessment of how such diverse identities such as daughter, wife and mother are negotiated on the basis of this knowledge, including the impact of a child with or without thalassaemia major, as examined in the current investigation.

The existence and nature of health promotion campaigns both within England and overseas, including the impact that they have in increasing debate and preventing the births of thalassaemic children, needs to be ascertained. While there has been a proactive public education approach in some non-Western nations in an attempt to raise awareness, and thus prevent such births (births that are seen as an economic and illness

burden), there have been very few similar initiatives in developed countries. Although the NHS Sickle Cell and Thalassaemia Screening Programme has attempted to achieve this by community outreach work and universal screening, this study will try to assess the perceptions and receptiveness towards public awareness and education in England and premarital screening and whether these may be viewed as socio-culturally and religiously acceptable among South Asian women.

As a consequence of this review of available literature, there are gaps within the literature as to how women of South Asian origin construct and give meaning to the  $\beta$ TT within the context of their everyday life experiences and identities. Moreover, the trait is a condition that has implications for the social and cultural roles that the women are expected to undertake, such as wife and mother. The meanings and subsequent management of genetic information will be impacted by the method of trait diagnosis and information delivery during the counselling process, as well as previous exposure that the participants may have had to the thalassaemia trait or major within personal and social contexts. Finally, there is relatively little literature, of how genetic risk is disseminated in Pakistani families and the dynamics of such potential dissemination (With the most recent examples being: Shaw & Hurst, 2008; Shaw & Hurst, 2009). Therefore, the objectives of this study are to address these gaps and to bring together diverse experiences in order to ascertain how South Asian women create social, religious and cultural meanings of the knowledge that they carry about the trait and, in turn, the consequential implications.

The next chapter will present the methods used to carry out the current investigation.



## **CHAPTER FOUR: STUDY DESIGN**

### **4.1 Introduction**

As argued in the previous review of literature chapter, there is a scarcity of empirical evidence into the impact of a genetic trait upon minority ethnic women including understandings, interpretation and assimilation of genetic information. There is therefore a need to contribute towards the theoretical literature of how minority women manage the knowledge of having a potentially discreditable, and therefore stigmatising, attribute with respect to social, cultural and religious influences. In order to answer these questions, the design and specific methods of data collection, sampling and analysis was informed by an approach that allows women to narrate their experiences within the context of their socio-cultural and religious influences.

This chapter will discuss the methodological considerations that influenced that theoretical approach and then the methods adopted to conduct this research study. In essence, this chapter will catalogue the research ethics process, recruitment and subsequent data collection and analysis in chronological order as it is my intention to discuss these processes in a more reflexive manner in the following chapter in order to avoid repetition.

### **4.2 Methodological approach**

Kathy Charmaz (2006:15) regards research methods as ‘tools’, the informed utilisation of which result in the appropriate collection and analysis of the data that will answer the research questions. As such, the study design was primarily influenced by the research

problem (Charmaz, 2006) which focused on the impact of living with the  $\beta$ TT and the attendant socio-cultural and religious influences in interpreting and managing that trait within the context of personal identities.

Although both qualitative and quantitative research paradigms can be used to verify and/or generate theory (Punch, 1998), verification or quantitative studies typically begin with a theory from which hypotheses are deduced and the study is designed to test the hypotheses (typically using quantitative data). For example, historically, women's health has tended to be discussed from the quantitative reductionist perspective - although this is changing (Schuiling & Likis, 2006). That particular viewpoint has resulted in theory-based conceptions of women's health from normative data which do not represent the in-depth range of women's health or illness experiences and ignore contextual factors which directly impact upon health. For instance, in the medical model, breast cancer is a potentially life-threatening disease with physiological origins and, as a result, responsibility for management lies within the clinical domain. Writers such as Rosser (1981) have applied a more qualitative approach to breast cancer to illustrate the impact of the illness in a wider psychosocial perspective.

With its focus on the aetiology of the disease, the medical model predetermines what data will be collected and what constitutes priority information, such as the need for clinical data. Clinicians have traditionally assumed this model to be an adequate base from which to understand and interpret the entire experience of having breast cancer, which is further reinforced by excluding phenomena outside the biomedical frame of reference. In the same way that a biomedical perspective omits the social, cultural and

religious aspects from the analysis of women's experiences of breast cancer, a biomedical focus on beta-thalassaemia may also exclude the same fundamental experiences which women may use to make sense of the  $\beta$ TT. Although biomedical research has made important contributions towards understanding epidemiological and clinical factors of population health, it has added little towards understanding the unique and individual health experiences arising from being a woman, for example (O'Donnell *et al.*, 2004).

In studies which *generate* data, theories are developed systematically from the (typically qualitative) data which remain grounded to the participant's world view. This has been illustrated in the following assertion by (Marshall & Rossman, 1989:82)

*"[the] participant's perspective on the social phenomenon of interest that should unfold as the participant views it and not as the researcher views it."*

As such I wanted to explore, from the participants' perspective, their experiences of having  $\beta$ TT and what it means to 'the self' as woman, mother, wife and so on. In addition, I wanted to examine how genetic information was assimilated and then disseminated - if at all. Due to the paucity of this theoretical knowledge, I felt it imperative to implement a research design which would allow for the exploration and interpretation of relevant phenomena without imposing preconceptions or existing theoretical frameworks. In addition, I took the theoretical perspective of Social Constructionism, which claims that meaning is not discovered but constructed (Crotty, 1998), to understand how women's constructed realities impacted on how they negotiated and managed the knowledge that they carried the  $\beta$ TT in relation to how they

interpreted their symbolic cultural roles and expectations (Goffman, 1958; Goffman, 1990), it was thought that a grounded theory approach encompassing the symbolic interactionism framework would better fit the aims and objectives of the study.

#### **4.2.1 Symbolic Interactionism**

Symbolic interactionism is one of the major theoretical perspectives in sociology. In its early days, both Max Weber and George Mead emphasised the subjective meaning of human behaviour, the social process and pragmatism. Mead, a social psychologist from the Chicago sociological tradition, in his study *Mind, Self and Society* (Morris, 1967), asserted that human beings continually derive meaning from, and thus adapt themselves, to a world that is constantly changing. These meanings can be modified through a process of interpretation, which enables them to deal with, for example, social or cultural encounters. Herbert Blumer established this concept as a symbolic interactionism framework and gave it a research perspective (Blumer, 1969; Porter, 1998). These tenets were further developed by Goffman (1990), who had an interest in analysing interactions in social settings and Becker, whose theories of deviance and labelling (Becker, 1963) suggested that social groups maintained order by making the rules whose infractions constituted deviance. Applying the label of deviant to those who broke rules allowed social groups to consider them outsiders.

As such, this study endeavoured to ascertain how the βTT manifested in social interactions within the following principles. First, women's perceptions of the trait will be based on what it means to them – a concept known as Thomas's theorem: "*what is*

*defined or perceived by people as real (such as perceptions of negative consequences or sanctions), is real in its consequences*” (Thomas & Thomas, 1928:72). Second, those meanings are defined through interactions with others, which will ultimately decide whether a trait is perceived as a negative condition and consequentially disclosed or not. Third, meanings of the trait can change over time as a result of experience, circumstances and interpretation. For example; women may initially face pressure to adhere to cultural values and expectations, such as being healthy and able to produce healthy children, and a trait may seem to be a barrier in achieving this. Once she has, she may feel more secure in her status as a mother of a healthy child thereby rendering the trait to a more secondary position.

#### **4.2.2 Grounded Theory**

Grounded theory as an approach (Denscombe, 2007) is believed to be the ideal approach “*in investigations of relatively uncharted waters*” (Stern, 1980:20) when significant variables in the health/illness situation have yet to be identified, as was the case for many aspects of this study. Stern further asserts that the grounded theory approach is the most suitable approach to undertake when a descriptive theory, for example, is not available, or there is a need “*to gain a fresh perspective in a familiar situation*” Stern (1980: 20) such as a fresh perspective on a health issue that is inherent within South Asian communities. In selecting grounded theory, the researcher – participant relationship becomes the interactive context within which the researcher begins to understand the perspectives of women, their ways of coming to know their

health issues, the strategies used to deal with such issues and the processes that help them through the situation.

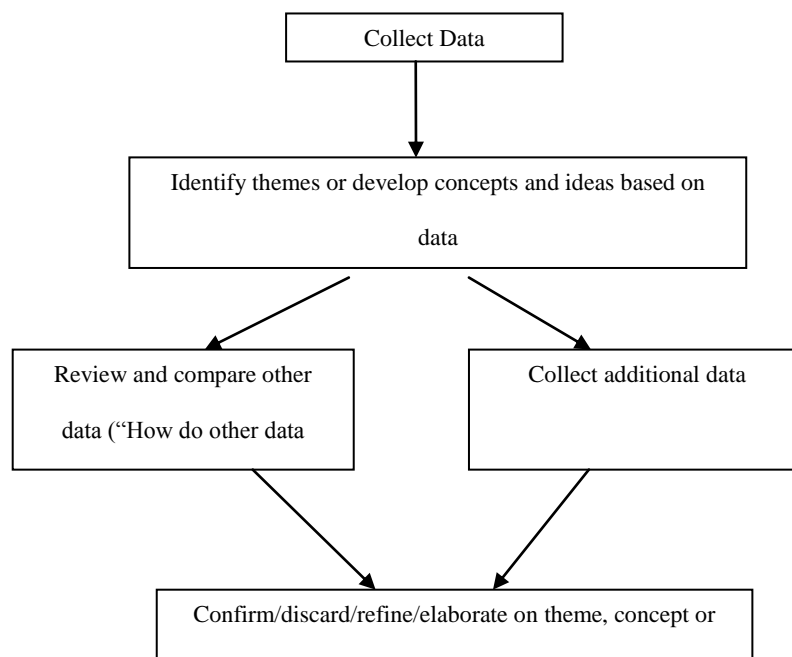
One common feature of the grounded theory dynamic is a focus on social behaviour, problems and processes. Grounded theorists in the past have explored the social processes of 'becoming' an alcoholic (Bigus, 1996), 'cutting back' after a heart attack (Mullen, 1993), and 'acquiring' specialist nursing expertise (Bonner, 2001) as well as the pioneering study by the grounded theorists Glaser and Strauss in their research on the process of 'dying' among hospital patients, which resulted in their book 'Awareness of Dying' (1965). As such, the behaviours of women with a hereditary trait, which may have consequences for reproductive choice and therefore be subject to stigma, fall within these parameters of 'becoming' someone or 'acquiring' something that has yet to be defined.

Whilst the writings of Herbert Blumer have focused on the dynamics of symbolic interactionism, they did not provide guidance on how to proceed with the collection and analysis of data. This deficit was overcome by the publication of various texts on grounded theory by writers such as Charmaz, (2000); Dey, (1999); Locke, (2001); Strauss, (1987); Strauss & Corbin, (1990); Strauss & Corbin, (1998) and Strauss & Corbin, (2007), which have provided guidance to researchers for collecting, analysing, interpreting and conceptualising data.

The aim of this thesis was not to produce pure theory (Glaser & Strauss, 1967) but to generate new understandings of women's self perception in relation to carrying a

recessive hereditary disorder. As such, rather than create theory, I modified the grounded theory approach by drawing on existing social theories to inform and better understand the female participants' experiences and followed what can be considered a pragmatic approach which is outlined in figure 10:

**Figure 10: Graphical representation of the grounded theory approach**



Source: (Taylor & Bogdan, 1998:138)

### 4.2.3 Study Methods

This was an exploratory study, the 'who', 'what', 'where', 'how' and 'why' questions (Yin, 1994) would not comfortably fit into a positivist paradigm and, therefore, a qualitative approach was adopted. Semi-structured interviews offered insight into individual thinking that, in Goffman's (1958) terms, is articulated 'behind the scenes'.

The actual interview process will be discussed in a later segment of this chapter; suffice to say that semi-structured interviews were considered an ideal way of achieving the appropriate balance between keeping some element of structure and uniformity in the data collection whilst allowing the participants to raise and discuss issues which they felt were important and relevant to the topic of conversation. Interviews were supplemented by field notes.

## **4.3 The Study**

### **4.3.1 Eligibility Criteria**

To be eligible for inclusion in this study, women who had the  $\beta$ TT were required to meet the following criteria:

- Be of South Asian origin (either they themselves had origins in India, Pakistan and Bangladesh, or their parents and grandparents did).
- Be aware that they had  $\beta$ TT
- Be over the age of 16.

Women who would not be able to give informed consent to take part in an interview with the researcher were excluded.



#### **4.3.2 The sampling strategy and selection of sites**

Multiple sampling strategies were used for the purposes of participant recruitment. Initially, sampling was purposive (the selection of participants with a certain attribute: South Asian women who had been diagnosed with  $\beta$ TT) and included variation in terms of age, religion, educational background, employment, having children with  $\beta$ TM, experiences of prenatal screening services and so on. As the study progressed, sampling became theoretical, by which subsequent participants were recruited to help achieve data saturation in key themes as well as to seek out potential deviant cases (Strauss & Corbin, 1998; 2007).

Due to resource constraints, I had originally selected three London Boroughs based on their concentration of South Asian inhabitants. Data from the 1991 Census was used to initially select the case study areas (Owen, 1992), cited in (Mason & Tapinos, 2000) and subsequent results from the 2001 Census have supported this initial selection. However, as the study progressed, I made a decision to recruit participants from a variety of different geographical locations such as the West Midlands and Northern England. Although both these additional regions had large South Asian populations, the primary motivator of including these sites was that, according to Modell et al (2000a), provision and uptake of prenatal screening services became sporadic outside London and especially in the West Midlands. As a result, I decided to incorporate this sample in order to obtain a divergence of experiences in the screening process and pregnancy management between those participants in London and other parts of England.

### **4.3.3 Geographical settings**

Three London Boroughs were chosen: Boroughs A, B and C. Boroughs A and B had a high density of South Asian populations while Borough C consisted of a dominant mix of white and African Caribbean. Additional research sites consisted of a city in the West Midlands and a city in the North of England which were chosen because of their history as former industrial towns with long-established South Asian populations. The study site profiles have been assembled using data from the Census 2001, local government profiles and Indices of Multiple deprivation (Communities and Local Government, 2004).

#### *Borough A:*

Situated in East London, it has an ethnically diverse population with many cultures, traditions, languages and age groups, with a significant proportion of its population between the ages of 20-44 years. South Asians, specifically those with Pakistani origins, form the second largest minority ethnic group after black African-Caribbean. Qualifications and skills levels are very low, with a smaller number of pupils achieving five or more GCSEs at grade A compared to the national average. Poor educational attainment has resulted in a smaller number of its population classified as having high levels of skills. The Borough, with its high levels of unemployment and crime, features highly in the Index of Multiple Deprivation which shows this borough to have high levels of deprivation both within local and national comparisons. The standardised mortality ratio is also slightly above the national average, which may in part be explained by the higher than national averages of cancer and circulatory disease.

*Borough B:*

Situated in inner London, this borough has a large minority ethnic and young population with over a quarter being under the age of 20 years. South Asians, mostly consisting of those with origins in Bangladesh, make up almost 40% of the borough's BME population. Although this borough has one of the largest economies in Britain, underpinned by vibrant financial and business centres, it is nevertheless one of the most deprived boroughs both within London and nationally. Unemployment rates are much higher than both the London and national average, which suggests that much of its knowledge-based workforce commutes from outside the borough. Although the numbers of pupils achieving five or more GCSEs at grade A are improving, they are still low compared to the national average, which is reflected by the low levels of qualifications and skills. This borough has the lowest life expectancy for both men and women in the whole country, exacerbated by the higher than national average of circulatory disease and cancer.

*Borough C:*

This borough has an ethnically diverse population with a younger age profile. While the majority of the population is white British, a significant part of its BME population comprises African-Caribbean and a high number of refugees. There is a relatively small South Asian population (5% of the BME group). This borough comprises a diverse socio-economic profile in that, while it is considered one of the most deprived within London and nationally, it also includes affluent wards which house some of the wealthiest people in the city. Educational attainment is also poor, with fewer than 50%

of its students achieving five or more GCSEs at grade A - much lower than the national average. This is reflected in higher levels of unemployment and a low skills base. Life expectancy for both men and women in this borough has tended to fall far below the national average, which was impacted upon by the high rates of circulatory disease, diabetes, stroke and cancer.

*City in West Midlands:*

This is an ethnically diverse city with a wide range of cultures, religions and nationalities, in common with the other geographical research sites. It has a young age profile with a large segment of its population between the ages of 20-24 years. The majority of the population is white, with approximately 30% from minority ethnic groups. Pakistanis comprise the larger proportion of the South Asian population, with just over 10% of the overall population of the city. The Pakistani and Bangladeshi populations have the highest percentages of its 16-24 year olds achieving no qualifications. Of the South Asian groups, Pakistani and Bangladeshis were less likely to be in paid employment or actively seeking employment, which is mainly provided by the service and telecommunications sector. In terms of health, consistent with the other research sites, there is a higher rate of premature mortality for both men and women, exacerbated by high rates of circulatory disease and chronic liver disease.

*City in Northern England:*

This city is not as ethnically diverse as the previous research sites. It is a predominantly white population with just over 10% from ethnic minorities, mostly consisting of South Asians of Indian descent. There is, however, a sizeable Pakistani community who

mostly reside in the wards which are considered among the most nationally deprived. Large parts of this city are affected by high levels of multiple deprivation including high crime rates. Educational attainment is also poor, with just over 49% of its students achieving five or more GCSEs at grade A - lower than the national average. This has resulted in higher levels of unemployment and a low skills base, which is reflected in the manufacturing and retail industries that are the major employers. In terms of health, life expectancy is lower than the national average and is affected primarily by alcohol-related health issues in addition to coronary heart disease.

#### **4.4 Research ethics and governance**

Research Governance Frameworks outline principles of good practice (Department of Health, 2001b; Department of Health, 2008). These ensure that research involving NHS patients, staff, organs, tissue and so on is independently reviewed, meets rigorous ethical standards and respects the dignity, rights, safety and well-being of participants so that any potential risks would be minimal.

Research governance and ethics processes have significantly changed since the time data was collected for this study – an issue that I will discuss in a more reflexive manner in the next chapter. However, in order to recruit participants from NHS sites, I was required to obtain approval from the Research and Ethics Committees of three London hospitals chosen in this project as, at that point in time, applications had to be presented to the ethics and governance departments of each individual NHS Trust. Prior to the application, initial contact was made with haemoglobin nurse specialists or counsellors

who, in turn, recommended consultant haematologists with whom they worked as the named collaborators (or principal investigators) for each of the study sites. Meetings were initiated with those consultants, where we discussed research aims and objectives, the interview topic guide and the actual recruitment process. Subsequently, I initiated the ethical approval process.

Research governance officers in each of the NHS Trusts were contacted and discussions included the use and storage of confidential information as well as interview transcripts, tapes and participant details in accordance with the Data Protection Act (1998). One NHS Trust suggested I obtain an honorary contract enabling me to work directly with haemoglobin nurse specialists or counsellors and thus have direct access to patient records. This was applied for and approved. The applications were submitted by the required date. In due course, I was asked to provide additional information; for example, I was asked to consider issues of health and safety and to provide information to the committee about any steps taken to ensure my personal safety in the field. A reply was duly sent stating the steps that would be taken, such as informing another party as to the time and location of interview, to confirm interview before attending, to have the interviews during daylight hours as far as possible and to always carry a mobile phone.

#### **4.5 Recruitment of the research participants: the formal approach**

Subsequent to obtaining ethical and research and development clearance, I received an honorary contract in two of the London Borough Trusts (A and C) and began the patient

identification process. Meetings were held with the principal investigators of each site and I was given permission to access details of women who were recorded as carrying  $\beta$ TT from ante-natal clinic records. At that time, I also interviewed two counsellors (one from London Borough A and another from the West Midlands) so that they could provide me with an insight of the screening process and the issues that they had faced in counselling South Asian women. The antenatal records were accessed and analysed to identify women of South Asian origin who had been diagnosed with the  $\beta$ TT within the past five years. This was not as straightforward a task as I had anticipated as the ethnicity recording of patients was sporadic - a problem which continues to this day (Jacobson, 2008). A physical inspection of the records was therefore undertaken searching for names that sounded South Asian where ethnic recording was not available. This process may potentially have been aided by the use of name recognition software programmes such as *Nam Pehchan*, which have been tried with varying degrees of success by researchers (Cummins *et al.*, 1999). However, it should be recognised that these programmes still need researcher input to identify South Asians with Christian names for example and, due to the fact that this was a doctoral research study with limited resources, I decided not to utilise this approach. With regard to Borough B, a patient advisor who spoke Sylheti (Bengali dialect) acted as a recruiter for the study as the researcher did not speak the language. This advisor recruited ten Bangladeshi women willing to be interviewed.

In addition to ethnic background, an assessment was made of the language most likely to be spoken from the information provided in the antenatal records. Study information

that was to be sent to potential participants was translated into the appropriate language (Urdu, Hindi, Punjabi and Bengali) and then proofread by a professional translation company which had extensive experience in both academic and medical translations. In addition, this material was then both proofread and checked for simplicity and clarity by myself, as well as contacts fluent in written Hindi, Punjabi and Bengali. The final study information packs consisted of the letter of introduction (see appendix 4) and study information for participants (see appendix 5) in English as well as the appropriate South Asian language. Twenty-five packs were sent to identified women in both Boroughs A and B and ten were sent in Borough C.

The letter of introduction (see appendix 4) introduced myself as the researcher, explained the project and invited the identified woman to participate in the study. The letter also stated that I would telephone each woman in order to answer any further questions and invite them to take part in the project, that participation was entirely voluntary, that refusal did not impact in any way on any treatment that they may be in the process of receiving and was sanction-free. It is, however, worth mentioning at this point that even though I was able to initiate contact with participants in this manner in 2002/2003, direct researcher contact in this manner would not be deemed permissible by an ethics committee in current times – an issue and its implications for research which will be discussed in greater detail in the following chapter.

Contacting the potential participants proved to be more difficult than had been originally anticipated as some of the women had moved and left no forwarding address. In Boroughs A and C, six or seven women had either moved or were not returning



phone calls, which may have been also due to various reasons such as a change of phone number or that many South Asian women visit their homelands for extended periods of time. Those whom the researcher managed to contact were either too busy (4 women), felt that the trait didn't affect them at all so they did not feel the need to talk about it (5 women), or were nervous about the research process and did not want to talk to a researcher (3 women).

Hussain-Gambles (2004) has written extensively about the issues of providing translated research materials to groups such as South Asians. She asserts that *“Even if the resources were available to translate the study information sheets and the consent forms into a number of different languages, assumptions are still being made that they will be read and understood by potential trial participants. High ‘illiteracy’ rates were highlighted in South Asian patients who attend Bradford hospitals”* (p18). Even though I made every effort to ensure inclusion in terms of information delivery such as recruiting a patient advisor to recruit Bangladeshi women and provide simplified translated information, I was nevertheless aware of the potential for illiteracy in both English and mother tongue. However, when subsequently asked, all of the non-Bengali women confirmed they were able to read the English or translated invitation themselves or their family members had read it out to them.

Informed consent is considered by the Research Governance Framework to be at the heart of ethical research (Department of Health, 2001b) and many researchers, for example Beauchamp and Childress (1991) have written about the importance of allowing people time to assimilate, provide feedback on, or even question study

information in order to provide voluntary and valid informed consent. In this case, I waited for ten days after the study information was sent out before making a decision to telephone women on the list so that, in addition to the written information, they had the opportunity to discuss the research in a language of their choice should they wish to do so. In doing so, I was nevertheless aware that telephone recruitment could be viewed as potentially coercive and took steps to ensure that when speaking to the probable participants, I explained that a) participation in the research was entirely voluntary and they could opt out at any point – up until and even at the interview stage, b) if they did not wish to discuss this matter further, they could end the conversation at this stage, c) that they would personally not benefit from the study itself and d) any NHS treatment that they were receiving would not be affected should they refuse to participate. After explaining the interview process, they were asked if they agreed to an interview, following which a date and time was arranged. Prior to attending the interview, I called each woman to confirm. Even so, in order to be fully assured that the consent given by the women was informed, I (or the interpreter where appropriate) repeated the information in the study pack and gave a detailed explanation of the consent form during the process of recording formal written informed consent prior to the actual interview.

Although there are advantages in utilising a verbal approach to recruitment, especially in cultures with strong oral traditions, such techniques can also lead to anxiety, especially when researchers are uncertain of the reaction they get from participants they are trying to recruit. Johnson and Clarke (2003:245) have highlighted the impact of this

initial telephone contact on researchers who are conducting studies on sensitive issues, with some researchers admitting to feelings of nausea: “Sometimes I felt physically sick before phoning them... it was like a minefield...I didn’t know what to expect....I would put off making the calls and then I would pluck up the courage”. These feelings were mirrored during the recruitment phase in this study when I began to telephone women after the allotted time period. Perhaps due to my position as a novice researcher having to undertake this process for the first time, I was anxious about the reaction I would receive from members of communities that are sometimes oversaturated with research, in addition to the fact that  $\beta$ TT is a sensitive subject and women may not want to discuss it with a stranger over the telephone. Indeed, one participant did express cynicism about the research process at the end of the interview when I asked her how she felt about taking part in research, as the following quotation shows.

*“I’m busy with children, you know. A lot of times people do their little projects into the ethnic minorities; you know gore [white people] and you sit there thinking ‘as if YOU care’. You know, it’s just time consuming.”*

(Participant 1. Pakistani Muslim aged 23. Married, not at-risk couple. Two children, trait status unknown.)

Expecting negativity and hostility, I, too, developed an aversion to telephones during this process and felt that the experience had become physically and mentally exhausting. Many times I would dial a number only to lose courage, or would decide to read an article, make a cup of tea or even attempt a pile of ironing – anything to put off that phone call. As it turned out, I was not subjected to any hostility and, although the majority of women were very receptive towards the project and agreed to the interview,

many did ask questions about the study; for example, one woman required more details about the research and another two women questioned the benefits of such a project to themselves as well as to the general South Asian community. In addition, at least one woman sought the permission of her husband during a telephone conversation with the researcher, and four discussed the study with family members before agreeing to participate in this project. Although initially seeming to confirm Brannen's (1988) experiences, in which she suggested that women may involve family members in deciding whether to participate in research and employ their husbands' refusal as a strategy of withholding participation, this did not knowingly occur in this study.

#### **4.6 Recruitment of the research participants: the informal approach**

The informal approach involved utilising contacts made in support groups in the North of England as well as through a thalassaemia major conference held in the West Midlands. In addition, I networked with people in local community groups and provided them with study packs to give to people whom they knew met the research criteria. Throughout this entire process, I made it clear to the contacts that confidentiality was to be maintained and that potential participants were not placed under undue influence (Semaan *et al.*, 2009). These approaches yielded a total of eight participants. The total number of participants recruited from both methods is detailed in the following table:

**Table 3: Recruitment of the participants from NHS and informal field sites**

Area of recruitment	Borough A	Borough B	Borough C	West Midlands	North of England
No of participants	19	10	6	4	4

#### **4.7 Piloting the study**

Prior to the main recruitment and data collection stage, I carried out a small pilot study in order to identify any potential issues that arose when recruiting women with potentially stigmatising conditions. The informal approach primarily consisted of networking with community groups to recruit a participant with  $\beta$ TT and then, in turn, asking those participants to recruit female acquaintances whom they knew carried  $\beta$ TT – a strategy known as ‘snowball sampling’ (Salganik & Heckathorn, 2004). As such, both these strategies enabled recruitment of participants. For example, one participant was recruited by her sister who had  $\beta$ TM and two others were recruited through community groups. The fourth participant was a haemoglobinopathy nurse specialist who acted as a counsellor in a London borough. In addition to testing the recruitment strategy, interview schedules were also tested, and subsequently amended, to include extra questions probing the partner’s reactions to the participant’s disclosure of a trait as well as views about termination.

#### **4.8 Participant sample**

The final participant sample included women of diverse socio-economic, educational, familial and ethnic backgrounds (Appendix 1) as well as women who had a child

diagnosed with  $\beta$ TM (n=6) and, in this way, the life experiences of women with  $\beta$ TT could be the focus of the research rather than undertaking recruitment to obtain statistical generalisation. A total of forty-five participants were interviewed, consisting of forty-three women who had the  $\beta$ TT and two genetic counsellors. The level of education in the participant sample was an important consideration in that I wanted to know if having a higher level of education impacted on how women understood and managed information of having a potentially stigmatised condition. As such, the educational attainment of the participant sample was varied and the sample included women who had completed university education both in the UK and their countries of origin. Only two women had not received any education at all (Table 4). Even so, women who were not very fluent in English generally tended to have a certain amount of literacy in their mother tongue due to their primary education and agreed to receive language-specific information about  $\beta$ TT when asked at the end of the interview.

**Table 4: Details of educational levels achieved by participants**

Education	Number of participants
University	10
Further Education	5
High School	9
Primary	17
None	2
Total	43

Although the majority of participants or their partners were employed in the service industry, there was variation in their occupational classifications and the sample

included university qualified professionals, including scientists, as is highlighted in the following table:

**Table 5: Occupational characteristics of participants or partners**

Own or partner's Standard Occupational Classification	Number of participants
Manager/senior official	1
Professional occupations	4
Associate professional and technical occupations	3
Administrative and secretarial occupations	1
Skilled trades occupations	3
Personal service occupations	0
Sales and customer service occupations	16
Process, plant and machine operatives	5
Elementary occupation	0
Unemployed	9
Student	1
<b>Total</b>	<b>43</b>

Source: Occupation classifications are taken from the Office for National Statistics, (2000)

#### **4.9 Data collection: interviews and fieldwork**

As a South Asian Muslim female who is immersed in her culture, I was aware of the need to adhere to certain forms of etiquette when entering the field. Being aware of how forms of dress are perceived in traditional households, I tended to wear traditional clothes in the form of a shalwar kamiz (a long tunic and trousers) as opposed to skirt and blouse as I may have been perceived as too Westernised, which may have impacted upon how I was viewed by the participants and, as a consequence, how much and what kind of information they felt able to divulge – a point also made by Darr (1990). Interviews typically lasted for an hour and were undertaken in the participant's own home. Prior to the actual interview, I explained the study and invited questions from the participants. In addition to explaining the study, I also took time to explain the Western concepts (McGee, 2006) of confidentiality and anonymity as, although they are embedded terms in Western research, they may not be understood by women from different cultures as safeguards against identification and participant protection. I felt that this was especially pertinent as I was, to a certain extent, an insider (by virtue of being a South Asian woman and a Muslim) and, as such, women may have the fear of sensitive information being divulged to the wider community as a result of an unguarded remark in a social situation (McGee, 2006). Once the participants indicated they were happy to progress, I started the process of recording informed consent in the form of a pre-prepared consent form which they then signed (Appendix 6).

The interviews were audio taped with the participants' permission after the process of confidentiality had been explained. With the exception of one participant who felt



uneasy about her voice being recorded, all of the women agreed to the recording of the interviews. After the interview, I generally had to stay and have a cup of tea or even a snack afterwards as a refusal would have been construed as ill mannered – especially in cultures (such as South Asian) that have an inherent tradition of providing hospitality. Such dynamics of the interview setting resonate with many researchers who have worked with such communities and have also pointed out the importance of food as a ritual for welcome and hospitality (Bush *et al.*, 1998).

The interviews were conducted in a variety of languages. Being fluent in Urdu, English, Punjabi and Hindi I was able to conduct those interviews which in some cases involved switching between English and either Urdu, Punjabi or Hindi within the same interview. The exception was the interviews conducted in Sylheti, which were carried out with the assistance of an interpreter who was already employed as an interpreter in the hospital patient liaison service (see table 6). The interpreter was briefed about the study and the importance of verbatim translation - even if the responses were deemed to be obvious prior to the interview. Furthermore, following the interview, there was a debriefing session in which the interpreter spoke of her perception of the interview process. However, even though I had made every effort to ensure that the interpreter understood the process, there were instances during the interviews where a lengthy conversation between interpreter and participant would be conveyed to me as a 'yes' or 'no' response. Evidence suggests that similar issues are common when working with interpreters (Pitchforth & van Teijlingen, 2005) and, as a result, there is a recognised need for professional interpreters who are trained in undertaking research.

**Table 6: Languages used during interviews**

Language in which interview conducted	Number of interviews
Predominantly English	14
Predominantly Urdu	8
Predominantly Punjabi	6
Predominantly Sylheti	10
Predominantly Hindi	5

Following the review of the literature in chapter three on various issues such as meanings of illness, genetic disorders, women and issues of gender dynamics and reproduction and power, a semi-structured interview schedule was designed as a framework with which to ask the appropriate questions (Appendix 2). Questions were asked of each participant in a systematic and consistent order, although with some freedom for the interviewer to digress and probe, allowing the participant to ‘tell her story’. In keeping with the nature of grounded theory, the questions were structured around key exploratory themes and the schedule evolved, as did the data collection, to incorporate emergent themes.

#### **4.8 Translating and transcribing the interviews**

It can be reasonably surmised that the translation and transcribing of interviews into English cannot be verbatim as they may lose meaning. However, the reliability of the

analysis can become difficult, with so much relying on the quality of the translation. Therefore, in order to keep an element of consistency, I personally undertook all of the translation and transcribing using the aid of a dictionary where necessary, as well as consulting with other multilingual researchers in the field. Where issues in translation arose, they were generally discussed with my primary supervisor and South Asian counsellors, an example being no direct translation for many phrases or words, for example 'gene'. Subsequent to discussion, it was felt that it would be better to contextualise the translations of the interviews while bearing in mind the risk of losing information during the process (Davis, 1999). In addition, however, it was recognised that some frequently used phrases may have different meanings both in the contextual and literal translation. For example, the Urdu phrase 'bachaa gira dalna' means in the literal sense 'dropping a child'. However, in the contextual sense when discussing the management of pregnancy, it refers to the termination of a pregnancy. Where difficult terms occurred in the interview transcripts, I bracketed the English meaning so as to give context to what was actually being discussed.

The transcribing and translation-and-transcribing of interviews was a lengthy and arduous process. A sixty-minute English interview took on average six hours, while an interview that needed to be translated took almost double that time.

#### **4.9 Analysing the interview data**

I had originally begun this process with the intention of manually coding and analysing the data in order to 'become closer' to it. However, such intentions were speedily

abandoned when the size and magnitude of the task became apparent. Consequentially, a decision was made to use a Computer-aided Qualitative Data Analysis Software programme (CAQDAS) since it assists the management of data by systematic storage, easy refinement of codes and rapid retrieval of data, and consequently enables researchers to engage with both the data and analytical processes in more detail (Dey, 1995; Lonkila, 1995). Another factor in using computer software in the data analysis process is that it is thought by some qualitative researchers to add rigour to qualitative research in terms of using the search facilities, for example to assign attributes to data sets which could be compared at a later point (Richards & Richards, 1991). After undergoing a training session, I decided to use NVivo 2 and then 7 because of its user-friendly nature and relative ease in mastering the required level of analysis, and also because this computer package facilitates a grounded theory approach (Richards & Richards, 1994a; Richards & Richards, 1994b; Richards & Richards, 1995),

In keeping with the grounded theory strategy, transcripts were translated, transcribed and inductively analysed along with the field notes as soon as possible after the interview so that emergent themes and concepts could be incorporated into subsequent interviews and thus inform the direction of the research. These emergent themes included perceived cultural values, managing or negotiating identities, avoiding stigma, risk perception, understanding genetic information, management of pregnancy and so on. I followed a systematic approach in processing and analysing the data, much of which was derived from Denscombe (2007: 288) and included the following steps:

1. Preparation of the data
2. Familiarisation with data
3. Generating initial codes
4. Searching for themes
5. Reviewing emergent themes

The stages are detailed below in the context of the present research:

1. Transcripts provided the raw data which were used in the analytical process. This preparation phase also involved anonymising the transcripts by stripping them of identifiers.
2. Familiarisation refers to the process of becoming immersed in the data (Denscombe, 2007). Transcripts were read and re-read, and meanings, experiences and patterns were actively sought to gain an overview of the participant's experiences, as well as to provide a summary of the material as a whole. During this phase, notes were taken that provided the basis for generating the initial codes.
3. The transcripts were read and initially coded. Coding was undertaken using a computer assisted qualitative data analysis software (NVivo). The initial coding was then reorganised into categories. Deviant cases were actively sought and coded where

they occurred. As anticipated, the initial transcripts generated numerous codes. However, this coding scheme was continuously updated as the study progressed.

4. Once the initial coding and categorisation had been conducted, I was able to collate them in order to identify emergent concepts and themes (for instance, negotiating identities as a result of being a carrier) which were then fed back into subsequent interviews.

5. Emerging themes were reviewed and examined in relation to existing literature and theories and also by constant comparison across interview transcripts.

As an example, the following table will give an illustration of how a segment of an interview was coded to allow for the development of some of the emerging themes and concepts – in this case, for chapter 6.

**Table 7: Example coding of a data extract**

Data extract	Codes	Developing theme	Concept
I know if anybody's to say anything, if anybody's to talk in ours it's a stigma and you carry it even when you're going to get fixed up or anything... 'oh she's got that blood thing, she's got that blood thing' she'll be still sitting	People talking/gossiping  Stigma  Labelled  Marriage  Discreditable	Consequences of being labelled with a potentially discreditable identity	Managing knowledge as a carrier to prevent stigma

there when she's 45.	attribute  Consequences for woman		
And to be honest, nobody needs to know anything but say your partner when you're married you know what I mean?	Concealing trait  Divulging information  To husband after marriage	Strategic disclosure of trait only where necessary and after marriage	

#### **4.10 Credibility, dependability and transferability in qualitative research**

Although the evaluation criterion of qualitative research is different to that of quantitative methods due to the different paradigms within which qualitative focused research is conducted, it is still, nevertheless, important to establish rigour (Arksey & Knight, 1999; Merriam, 1995).

It has been argued that, due to the nature of knowledge in the interview setting being situational and conditional in that point in time, the traditional concepts of validity and reliability used in quantitative research cannot be replicated in the context of qualitative research. Corbin and Strauss (2007:50) further emphasise that not only are the dynamics of time and space impacting on the nature of data collection but that, due to the nature of qualitative research, more than one story can be derived from the same piece of data by different analysts. In light of these different dynamics, I followed the criteria suggested by Guba & Lincoln (1981), who propose the principles of credibility,

transferability, and dependability - corresponding to the traditional methodological criteria of internal validity, reliability and external validity - as appropriate steps towards attaining such rigour in the research setting. It is these criteria that informed the evaluation of the quality of data obtained in the current qualitative research study and they are the focus of the following discussion.

*Credibility:*

This was primarily achieved by the triangulation of multiple data sources, collecting data from various participants along the axes of age, social class, religion, risk status, geographical locations, recruitment strategies employed and parental implications of the women's trait. Peer/colleague examination of the data analysis and interpretation process was also utilised (Merriam, 1995) - in this case I drew upon the support of the supervisory team to determine the plausibility of the emergent themes. Another strategy was to remain cognisant of the researcher's place in the research setting and any preconceptions, biases and experiences that I as a researcher may bring to the research process, as discussed in more detail in the following section.

*Dependability:*

The concept of reliability or dependability still needs to be considered in evaluating qualitative research. Flick (2006):16) proposes that "*researcher's reflections on their actions and observations in the field, their impressions, feelings and so on become data in their own right forming part of the interpretation*". In keeping with this principle, I had documented the research and interview process by keeping a research diary (Appendix 7) in which I noted my experiences in the research setting. This had the



multiple functions of creating a record and providing material for reflection during data analysis, chronicling where possible the stages leading up to the interview - and as a consequence, leaving an 'audit trail' (Guba and Lincoln, 1981). Directly after each interview, impressions, ideas, reactions and insights were recorded in the research diary and in some cases reflected difficulties that may arise in qualitative inquiry (Nadin & Cassell, 2006). Many of the entries recalled the concerns I had of unintentionally portraying (especially Muslim) participants in a negative light in the aftermath of 9/11. This concern became more salient in one particular situation where the participant corroborated Western stereotypes of South Asians or Muslims as being fatalistic, as highlighted in the following quotation:

*"...the gore [white people] think we don't really bother, it's quite true in one way, I think our Asian people, we really don't care about these kind of things. We just keep it to Allah you know, praying and leaving it to Him. That's what I think. I really think we don't care, us Asians".*

(P3: Pakistani Muslim aged 25. Consanguineous marriage, at-risk couple. One child, trait status unknown.)

I found this view was rather disconcerting and began to wonder if I was indeed capable of reporting a particular situation 'warts and all' whilst reconciling my natural instinct of protecting my people *and* undertaking research and analysis true to the data, as the following entry about the above participant shows:

*"...This participant is angry. She and her sister are in consanguineous marriages with two brothers and I wonder if there is a sense of resentment (perhaps of the very marriage itself?). Although she has said clearly what a lot of Muslims may think, that our reliance on God is at the detriment of the intelligence He has given us to claim responsibility*

*for our own actions, do I really want to confirm that, especially to people who have a negative perception of us already? The public at large already think of Muslims as backward fundamentalists, do I really want to perpetuate this myth”?*

(Diary entry, September, 2002)

After discussions with fellow researchers in other institutions, including a great deal of soul searching, I came to the conclusion that my obligation as a researcher was to remain true to the data. Even though one participant had confirmed the stereotype, others may have divergent views. This is the advantage of using qualitative research in the study of communities since qualitative approaches allow the diversity of views held by communities to be given a voice and brought to light, as was the case in this study.

In addition to the ability to reflect, the diary also synthesised key themes emerging in a single interview, leading me to write prompts about issues to explore with subsequent participants. Events and strategies raised in previous interviews could then be followed up, for example perceptions of families ‘back home’ in the subcontinent. The research diary also detailed contacts made and meetings with gatekeepers as well as the field encounters themselves. The majority of entries made were retrospective so as not to break the momentum of the interview and for the researcher to reflect on the experience. These reflective observations were made directly on the same audiotape the interview was recorded on, which enabled the flow of analytical ideas to continue during transcription.

### *Transferability:*

Discussions about whether the findings of one qualitative study can be generalised to other studies are considered fairly problematic, especially in the interpretivist paradigm (Merriam, 1995). However, in trying to achieve external validity, the emphasis in qualitative research is on whether there can be a transfer of the findings to other research contexts. The strategies used in the current study to facilitate transferability (or reader generalisation) included: maximum variation sampling to identify comparative and 'deviant' cases, and an audit trail of the different stages of the research process.

## **4.11 Conclusion**

In conclusion, the focus of this chapter has been to explicate the background of the grounded theory methodology used for this study and describe the specific methods used for participant recruitment, data collection and analysis. The study was undertaken in five different field sites in England and involved 45 participants. The primary data collection method used for this qualitative, interpretive study was semi-structured interviews. Participants were interviewed once between 2002 and 2003, in the majority of cases, within the home setting. Interviews were recorded, transcribed and entered into a computer software programme in preparation for data management and coding, although data collection and analysis occurred concurrently. Secondary data collection methods included written field notes and a research diary. Although I have touched upon the issues of coercion and access that may arise due to the research and recruitment process, I have decided to discuss them in a more detailed and reflexive manner in the following chapter.

## **CHAPTER FIVE: THE DYNAMICS OF SENSITIVE RESEARCH IN A MARGINALISED POPULATION – A REFLECTION**

### **5.1 Introduction**

The previous chapter provided an overview of the study design, research and ethical governance considerations, the process of data collection and the approach adopted in data analysis. This chapter will now explore many of these themes, but in a more reflexive manner. I will consider the ethical issues that arise as a result of conducting a sensitive study with a minority ethnic population in general but also how my many shared identities as a South Asian, Pakistani and a Muslim, at a time of increased suspicions of Muslims and raised Islamophobia in the Western media, impacted on the research setting and data collection. This chapter also considers how the published ethical guidelines on conducting social research impacted on the process of recruitment and data collection. In documenting key issues surrounding the processes of negotiating access and the potential implications of participation for women, this chapter highlights the difficulties that may be encountered in sensitive research. In addition, it explores how these issues can impact upon the relationship between the participants and the researcher.

Due to the specific nature of issues arising from researching minority ethnic or marginalised groups, I feel a separate, reflexive chapter may be more appropriate as it allows me to reflect on what I did during the study, what I could have done better and

how subsequent studies have been undertaken with the knowledge and experience acquired from this particular study.

In order to provide a comprehensive illustration of the issues I faced as a researcher (and tried to overcome), this chapter will be sectioned into the following areas: 1) definitions of sensitive research, 2) issues in recruiting minority populations in research studies, 3) sensitive research and the interview setting, 4) handling emotions and 5) the researcher's position in the research setting.

## **5.2 Defining 'sensitive' research**

There are many definitions of what constitutes sensitive research. For the purposes of this study, the definition I find most appropriate is one by Renzetti and Lee (1993), who assert that sensitive topics are those that seem either threatening or contain an element of risk in some way. They conclude that "*sensitive topics are ones which include areas that are private or stressful or those that expose potentially stigmatizing conditions*" (Renzetti and Lee, 1993: 4). This study was considered to be of a sensitive nature due to two factors:

- 1) The socio-cultural implications of a hereditary disorder;  $\beta$ TT can be a potentially stigmatising disorder and may result in cultural sanctions. For example, if disclosed, it can create difficulties in securing marriage partners for carriers, especially if they are female (Hussain, 2005). Additionally, it raises potentially difficult reproductive issues for at-risk couples (Modell *et al.*, 2000a).

2) The impact of the research process on the participants; as a researcher, I was aware of the potential stress and emotion that the participants may have felt when revealing their stories (Dickson-Swift *et al.*, 2008; Lee, 2003).

### **5.3 Recruiting minority populations in research studies – (past and present)**

Even though previously discussed directives such as The Research Governance Framework (Department of Health, 2001b) have recognised the lack of minority participation in research and have made recommendations for diversity to be recognised in research studies (Godden *et al.*, 2010), trying to reach marginalised and BME groups can be a challenge. There is a general recognition that marginalised and BME groups tend to be under-represented in the research process (Allmark, 2004; Johnson, 2003; Ranganathan & Bhopal, 2006; Sheikh, 2005; Wendler *et al.*, 2005). This can be in part due to the assumptions of researchers themselves that people from those groups are unwilling to participate in research (Hussain-Gambles, 2004), which then leads to a failure to proactively reach out to those communities and encourage them to take part in the research process. In addition, as some writers such as Steele (2004) have cynically recognised, there is a ('convenient') tendency for the research community to label certain groups as 'hard to reach' which, in Steele's opinion, is an erroneous assumption as "*how difficult they are to reach depends on how hard you are prepared to try*" (p10).

As a result of these perceived barriers, many researchers have become reliant on facilitators such as community, faith and health support groups to access and recruit BME populations (Gunaratnam, 2003). Even though working with such gatekeepers

can have benefits in accessing minority or marginalised populations, it can also be challenging. Building and maintaining relationships with gatekeepers is a very time consuming and does not necessarily lead to recruitment (Rugkåsa & Canvin, 2010). In addition, researchers are reliant on the goodwill of gatekeepers to facilitate access to participants which may not be so forthcoming due to ‘research fatigue’ (Johnson, 2003) or paternalism (Rugkåsa & Canvin, 2010). Many gatekeepers from BME communities view research not as a mutually beneficial process, but as a one-way process with few results being fed back to them and the belief that there is little likelihood that they will ever benefit from the study findings (Johnson, 2003), particularly at the level of policy. This can result in gatekeepers withholding cooperation even though ethical approval has been granted, an issue highlighted by Wanat (2008). As a novice researcher, I was ‘wading’ into unknown territory when I began to initiate contact and build relationships with community gatekeepers. I was taken aback by the territorial nature of many groups I encountered which, with hindsight, is not so surprising considering that many are reliant on public funds and therefore need to justify their existence. Therefore, in order to foster goodwill, I constantly emphasised teamwork as part of the research exercise in addition to becoming more proactive, such as giving talks on thalassaemia. In contrast to my doctoral research, subsequent studies I have undertaken have involved both service users and user groups in the research process from the onset – a condition of the Research Governance Framework (Department of Health, 2001b) which requires that participants must be involved in the design, conduct, analysis and reporting of the research wherever possible (McGee, 2006). Indeed, involving traditionally marginalised groups has become an established sign of good practice recognised by

grant funding bodies that require evidence that such groups are involved not only in the design of studies but also the implementation, dissemination and administration of the study. Consequentially, user groups and/or gatekeepers have a vested interest in the successful completion of the study and are therefore proactive in recruiting participants, for example.

There has been a considerable change in ethics approval and data collection processes since I collected the data for this study. The 'research passport' has replaced the traditional honorary contact and streamlined the administration of multi-centred studies, thereby enabling researchers faster and more efficient site access for studies that have ethical approval. Policy drivers such as the Research Governance Framework (Department of Health, 2001b) has set in place mechanisms to ensure that any research undertaken in the NHS complies with "*all professional, ethical and scientific standards*" (Kerrison *et al.*, 2003:553). For example, researchers are now required to undertake training in Good Clinical Practice (GCP) which covers the design, conduct, performance, monitoring, auditing, recording, analysis, rights, integrity and confidentiality of trial subjects and reporting of clinical trials that provides assurance that the data and reported results are credible and accurate in order to obtain both research and development clearance and honorary contracts. Although GCP courses are primarily directed towards researchers working in clinical trials, NHS sites issuing research and development clearance now routinely insist qualitative researchers undertaking interview-based studies also undergo this training - as has been the case with studies I have subsequently undertaken nationwide.



The situation has also changed with regard to patient data and privacy. Although I was able to access identifiable patient records when I was identifying patients meeting the research criteria for this thesis, current procedures implemented by the Research Governance Framework (Department of Health, 2001b), in accordance with the Data Protection Act 1988, require that identifiable patient data can only be accessed in the first instance by NHS staff such as General Practice managers or primary care research networks. Where it has been necessary to access patient records, for example, to examine treatment undertaken for cancer, prognosis of illness, or in studies where data has been collected in a triad (a patient/carer/GP) perspective, I have been able to do so after discussions with Caldicott Guardians in NHS Trusts and incorporating the arising issues in my ethical applications. This has resulted in ethical, R&D and administrative approval conditional to including a section in written consent forms which explicitly asks participants for consent to access their medical records.

Research and Ethics committees, in conjunction with the Research and Governance Framework (Department of Health, 2001b), have had direct consequences for BME and marginalised groups recruitment by their focus on the 'opt in' approach. This focus on opting in as an example of good research practice has direct consequences for research, especially for minority populations who may not be receptive to recruitment techniques more successful in White majority populations (Hewison & Haines, 2006). Recruiting minority or marginalised groups requires a more proactive approach than 'opt-in' advocates realise - an issue that has been recognised by researchers working with such populations who suggest that strategies traditionally employed for recruiting white

majority populations such as mass mail outs and advertisements (Blumenthal *et al.*, 1995; Mohammadi *et al.*, 2008) simply do not work, especially where there may be issues in literacy. Aware of these issues, I decided to approach participants directly and discuss the study in a language of their choice, thereby providing as much information as necessary so that the women were able to make an informed decision whether to take part or not - a strategy that I am unable to employ in the present day. The present opting-in system requires a health care professional to make the initial approach to patients by sending or giving them a letter and study pack containing a response form allowing me to contact them. However, as a researcher, I am reliant on a) sufficiently engaged and enthusiastic health care professionals to promote and recruit for the study and b) potential participants taking the time to read the study information pack and responding. This can be especially difficult if the study is deemed sensitive; for example, in a recent study I undertook investigating children who had cancer, ethical permission was conditional to recruitment being undertaken by paediatric oncologists. This led to poor response rates and, as a result, a substantial amendment was applied for which enabled me to remain in outpatient clinics where interested patients could be directed to me. This proved more successful in recruiting participants but required long-term intensive input, which can be very resource-consuming both in terms of time and finance.

## **5.4 Sensitive research and the interview setting**

The Statement of Ethical Practice guidelines issued by the British Sociological Association (British Sociological Association, 2002) emphasises the researcher's

obligations in ensuring the physical and emotional safety of both the participants and the researchers themselves in the research setting. This is even more crucial in areas where the subject matter is considered sensitive enough to have ramifications for those who participate. For example, Brannen (1988) argues that women who reveal highly personal information about their lives are at risk either emotionally or physically from people implicated in interviews, such as husbands, as well as from potential exploitation from the researchers themselves. She goes on to add that:

*“Those who disclose details of their personal lives, especially if they are women, may be at risk from their partners. Men are more likely to be unhappy about disclosing personal information....they may experience anger if they later discover that, unbeknown to them, their wives have been taking part in a research project which involves talking about private matters.” (p560)*

As such, this chapter will now highlight certain principles of the *Statement of Ethical Practice* and illustrate how the researcher incorporated these into the research process.

Principle 16: *As far as possible sociological research should be based on the freely given informed consent of those studied. This implies a responsibility on the sociologist to explain as fully as possible, and in terms meaningful to participants, what the research is about, who is undertaking and financing it, why it is being undertaken, and how it is to be promoted.*

The principle of informed consent is a pivotal part of the code governing research. Arising as a consequence of human trials by Nazi doctors in concentration camps

(Faden & Beauchamp, 1986), it forms both a moral and socio-legal (Faden & Beauchamp, 1986) framework for the process of conducting research in both clinical and non-clinical settings. The fundamental principle is that the participation should be both informed and voluntary. Although I have discussed this in some detail in the previous chapter, the written consent form for this study (Appendix 6) as well as the invitation to participate (Appendix 4) was available in Urdu, Punjabi, Bengali as well as English. The language used was simplified to enable it to be comprehensible to participants. Even so, prior to the actual interview, I explained the study again, including each point in the consent form, to the participant in a language of their choice and invited questions. Verbal consent was reaffirmed at different points in the interview, especially if there had been a pause due to emotional upset.

*Principle 17: Research participants should be made aware of their right to refuse participation whenever and for whatever reason they wish.*

Edwards and McNamee (2005) suggest that research participants reserve unconditional or absolute 'right' of withdrawal at any time, without giving any reason and without fear of any present or future (health) treatment being compromised as a result. The introduction letter (see appendix 4) explicitly stated that I would telephone each woman, thereby removing the element of surprise. In addition to the procedure undertaken, which is fully explained in the previous chapter, I also remained aware of tacit changes in the tone of voice or hesitancy which may imply that they were uncertain or did not want to take part in the study but were too polite to say, especially to an insider researcher (Liamputtong, 2010). Suffice to say that the overall strategy of avoiding

coercion and maintaining informed consent was consistent throughout both recruitment and the interview stage and was written into information sheets and the consent form as well as being reiterated to participants during the consent recording process.

Principle 13: *Sociologists have a responsibility to ensure that the physical, social and psychological wellbeing of research participants is not adversely affected by the research. They should strive to protect the rights of those they study, their interests, sensitivities and privacy, while recognising the difficulty of balancing potentially conflicting interests.*

A sizeable amount of literature available on sensitive research and the interview setting is located in the field of women and domestic violence (Brannen, 1988; McCosker *et al.*, 2001). Although the subject matter was different in this study, the logistical aspects of researcher and participant safety and wellbeing was a priority from the onset. This priority was made apparent at the onset of the recruitment process, when I was faced with such an issue when a South Asian woman indicated she would be receptive to an interview but wanted me to come at a certain time when her husband was at the local religious venue and to leave before he returned home. After much contemplation, I decided against including this woman in the study because the potential threat to both myself and researcher was too great, a point highlighted by Hoyle (1998):41) who said that “*interviewers need to be sensitive to the dangers to which participants might be exposed as a direct result of the interviewer's presence.*”

Because of the fear of stigma, and therefore potential familial sanctions associated with the disclosure of a trait, interviewing a participant in her own home presented its own set of problems. I insisted that the participant was alone during the interview. Any relative that was present was asked to leave the room while the interview was being conducted but was told that they would be welcome to join us after the interview was concluded. On three occasions, the participant's spouse indicated that they too would like to take part in the interview as they felt that they were being ignored in this process. In response, whilst making every effort to be sympathetic, I had to insist that interviewing partners or other family members was not part of the remit for this particular project, but suggested that perhaps a separate study could be carried out in the future. However, once the interview was concluded, the partners would often come and sit with their wives where they would discuss the problems and issues they faced as either carriers or as partners of carriers.

Principle 14: *Because sociologists study the relatively powerless as well as those more powerful than themselves, research relationships are frequently characterised by disparities of power and status. Despite this, research relationships should be characterized, whenever possible, by trust and integrity.*

Whilst accepting that there is an inevitable power imbalance in the research relationship, “*even when the researcher has an intellectual and emotional commitment to the people being studied*” (Hammersley & Atkinson, 1993:274), I was nevertheless aware that my role as researcher in a research setting with vulnerable women may have the potential to be exploitative in that women may feel pressurised to divulge intimate

information. As such, the setting of the interview in the participants' homes can be problematic with regard to issues of participant confidentiality and vulnerability where extended family members are present. There were two incidents where I felt that there was no other option but to abandon the interview in order to protect the participant and, as a result, to maintain the integrity of the research process. For example, in one instance, the participant's mother-in-law was present and, despite requests for the participant to be alone during the interview, it became apparent that this was not likely to happen; consequently, I felt that I would not be able to conduct a proper interview. However, I asked the participant a few benign questions about her experiences of the health care system so as not to arouse the suspicions of those in the immediate vicinity, as I was aware that the extended family was not always aware of the woman's trait status. In another example, the interpreter asked the participant if her husband and in-laws were aware of her status. The participant then thought that I would divulge this information to her in-laws and became very upset and agitated until I emphasised the confidential nature of the interviews as the following quotation illustrates:

Researcher: *"She's scared because we're here?"*

Interpreter: *"She's saying em... why she's scared is if her in-laws know, they might think something of it."*

(Participant 34. Bangladeshi Muslim age 19. Married, not at-risk couple. One child, trait status unknown)

The participant remained very aware of the presence of her husband's family throughout the interview, which was concluded sooner than it would have, had such potential conflicts not been present. Both the interpreter and I realised that the fear of disclosure

was too great for this particular participant due to the possible repercussions that may arise, for example, stigmatisation, as has been cited by researchers in areas such as cancer stigma (Sankar *et al.*, 2006). Furthermore, the participant was a very young woman, a recent arrival in the UK, which could have been considered an alien environment, and no peer support networks, which added to her isolation even though she lived with her husband's family. She had just had her first child, which added to her sense of vulnerability.

On another occasion, asking the participant if she had ever heard of  $\beta$ TT led to a denial of either having had blood tests or having heard of the trait, even though her records showed antenatal blood tests and a trait diagnosis. Even though this participant may have been denying knowledge of the disease for fear that being seen to have knowledge of the trait would automatically implicate her as being a carrier (Dyson, 2000), I did wonder if she had ever received any counselling or whether her husband had been tested. After much deliberation, I felt I had no ethical choice but to abandon the interview as it was not part of the remit to 'inform' the participant of her trait status.

*Principle 8: Social researchers face a range of potential risks to their safety. Safety issues need to be considered in the design and conduct of social research projects and procedures should be adopted to reduce the risk to researchers.*

Although such considerations are now part of the ethics approval process, 'risk assessment' has traditionally focused on the researched rather than the researcher. Generally, researchers have tended to follow cursory health and safety rulings initiated



by their employers, disregarding their own personal safety in order to ‘get an interview’ (Craig *et al.*, 2000). However, in keeping with health and safety protocols, I did ensure that the location and time of the interview was known and, as an added precaution, I carried a mobile phone. There were times, however, when issues of safety had to be viewed pragmatically, for example, inner city London especially presented a challenge as one research site consisted mainly of tower blocks which had to be accessed, sometimes in the evening and, bearing this in mind, such visits were kept to a minimum.

Writers such as Day & Topp (2003) have questioned the practicalities of interviewing participants in their own homes both in terms of researcher and participant safety. However, mindful of the need for pragmatism (considering issues such as domestic responsibility, for example), the participants were given the option of being interviewed outside the domestic setting in venues such as a coffee shop, or a separate room in a health clinic. Nevertheless, all but one of the participants opted for home based interviews for reasons of convenience. The home environment was also thought to be more advantageous because, as Finch (1993):74) has suggested, “*In the setting of the interviewee’s own home, an interview conducted in an informal way by another woman can easily take on the character of an intimate conversation.*” Furthermore, a public environment is not always the best place to discuss intimate issues, as Day and Topp (2003) have shown. Women do not necessarily feel comfortable in these settings and, therefore, cannot discuss their feelings openly for fear of being overheard or seen by someone they know. Although one such interview was carried out in a supermarket café during a participant’s lunch hour, the atmosphere was not conducive to an intimate

discussion and it was difficult to hear and be heard with the lunch hour background noise (which made post-interview transcribing fairly difficult).

*Principle 36: Appropriate measures should be taken to store research data in a secure manner. Members should have regard to their obligations under the Data Protection Act. Where appropriate and practicable, methods for preserving anonymity should be used including the removal of identifiers, the use of pseudonyms and other technical means for breaking the link between data and identifiable individuals.*

As highlighted in the previous chapter, data resulting from this study was stored subject to the requirements of the Data Protection Act 1998. Transcripts were anonymised and participants' details and recorded demographic data were kept securely in a separate location. Due to the relatively small sample population from which the study recruited, I had decided at the onset of the study not to give the participants pseudonyms but to give them numerical designations as an additional strategy towards preserving their anonymity. In addition, geographical areas were grouped as Borough A, B, C and so on.

*Statement 13: Sociologists have a responsibility to ensure that the physical, social and psychological well-being of research participants is not adversely affected by the research. They should strive to protect the rights of those they study, their interests, sensitivities and privacy, while recognising the difficulty of balancing potentially conflicting interests.*

Due to the sensitive nature of the research topic and the fact that probing questions were asked about the impact of  $\beta$ TT in their lives, many (n=6) women, especially those who had a child with  $\beta$ TM, felt overwhelmed at times and recording had to be paused while the participant composed herself. This was clearly an emotive subject and in many cases the participant admitted to discussing her fears for her child and her own emotions for the very first time. They had never been asked how THEY felt and the feelings invoked were quite powerful. One woman admitted that sometimes her relationship with her  $\beta$ TM was strained:

*“He says to me that you're the bitch who's kept me alive...I tried so hard to understand and to help him; I wish I could take the thalassaemia instead of him so that I could cope with it better.”*

(Participant 41. Indian Hindu age 52. Married; At-risk couple. One child, major.)

There is a sizeable amount of literature discussing the researcher's responsibility towards the participant in an interview setting, especially where the subject is a sensitive one. The issue of protecting the participant from herself, especially if the interview is one that is emotionally taxing, is one that has been continuously discussed from two opposing viewpoints. Feminist writers (Brannen, 1988; Finch *et al.*, 1993; Oakley, 1981) have continuously emphasised the researcher's responsibility to safeguard the (emotional and, by implication, vulnerable) female participant from exploitation as she may divulge more information than she may do in other circumstance. However, a writer such as Massey (1996), for example, responds to this assertion by claiming that the belief that the researcher has responsibility for the emotional wellbeing of the participant, due to the fact that she managed to elicit more

information from her, is either over-estimating the researchers' skills or underestimating the participant's capacity for withholding it.

Ultimately, participants only divulge the amount of information they want and, due to the fact that I had established good rapport with the participants from the onset of the interviews, they were quite happy to discuss their issues and concerns with regard to being carriers and, in many cases, also talked about other concerns unrelated to their trait status. Participants discussed many issues of a personal nature, such as the states of the marriages and her relationship with her in-laws, without much prompting. This willingness to discuss intimate information was partially facilitated by my readiness to divulge information about myself when asked, as I felt that the strategic disclosure of personal information would not only facilitate rapport but also equalise the power inequalities between interviewer and respondent in a research situation (see Abell *et al.*, 2006; Oakley, 1981). Indeed, it became the norm for me to be served a meal or a snack after the interview, and for conversations to continue about dilemmas the participant was facing or for other general conversations to take place. At the end of each interview setting, participants would be asked if they would like more information about the trait or  $\beta$ TM in a language of their choice. The majority of the women indicated that they would and copies of the relevant information were subsequently sent by post. Subsequent to the conclusion of the data-gathering stage, links made with a few participants were maintained for a while and included undertaking advocacy work in areas such as welfare benefit information and attending appointments to interpret in local government offices and hospitals.

## 5.5 The researcher's position in the research setting.

The data collection phase for the main part of the study began after September 11<sup>th</sup> 2001, in 2002. The impact of that event was that communities (especially Muslim), who were already marginalised through a combination of communication difficulties, higher prevalence of long term chronic ill health, and socio-economic deprivation, began to find themselves under more scrutiny. Indeed, prior to the actual process of data collection, I had become aware of the unease within the Asian and, more specifically, the Muslim communities, which extended to an unwillingness to divulge information that was viewed as potentially damaging.

The post September 11<sup>th</sup> period (and subsequently post 7/7 and the Glasgow Airport attack on the 30<sup>th</sup> June 2007) have been marked by a discourse that has characterised relationships between white British and British Muslims as one of 'them' and 'us' or of 'these people'. Muslims especially have been expected to repeatedly condemn and apologise for the attacks, to explain and educate the wider community, to have their loyalties questioned and to remain silent if they disagreed with military actions in Iraq or Afghanistan. While the Home Office states that "*no community or religion should be made a scapegoat for the actions of terrorists*" (Home Office, 2004), Muslims felt that Islam had become synonymous with international terrorism. Muslims were vilified in the media, which labelled any terrorist act as Islamic, such as the headline "*Islamic bomb foiled*", leading to writers such as Amiel (2004) to question the entire Muslim community. This has led to actual violence from the wider community and strained relations with law-making authorities, as well as exacerbating already existing problems

in the form of employment, housing, education and other types of services that Muslims may access (Muir & Smith, 2004).

The end result was that communities who were already marginalised became alienated. Identities were in a state of flux. Who were we? Did we consider ourselves as British Asians, Pakistanis, Indians, Bengalis or did our identities have to be renegotiated in the face of circumstance? Indeed, what was the problem with the British psyche that they could not consider that people may have fluid identities? As a member of that very community, I, as a researcher, faced similar dilemmas in terms of my own identity, including concerns about the research process and whether I was opening up the Asian and, more specifically, the Muslim community to further scrutiny and negativity as a result. Foucault's (1994) account of the ways the medical gaze exerts highly specific forms of power and control in the regulation of bodies, and ultimately of populations, through 'disciplinary power' highlights this dilemma: by undertaking research into health beliefs and behaviour. Was I giving away too much information to people who may have ulterior motives and who may be seeking to control such communities under the guise of health promotion programmes? Consequentially, I was interested to ascertain how these communities viewed their participation in the study. The majority of Muslim women admitted to me that the only reason they participated in the interviews was that they felt the researcher was a South Asian AND a Muslim woman and, by default, she would understand the issues that these communities were facing and, as an insider, would not show the community in the negative manner they were

being portrayed in the press. This is illustrated in the words of the following participant (who also acted as a recruitment facilitator), who stated:

*“But you know, I said that it’s important to talk about this so other people will understand and she’s also a Muslim, you know, she’s one of us so we must help.”*

(Participant 29. Pakistani Muslim age 31. Consanguineous married, at-risk couple. Three children, one major.)

Although the majority of the participants came from Pakistani origin (n=22), there were many who were Indian from Hindu or Sikh as well as Muslim backgrounds. In a separate situation, another international incident gave rise to concern with regard to the research setting. I was extremely concerned about the potential impact of the conflict between India and Pakistan concerning the issue of Kashmir on the recruitment and interview process. Both countries had gone to war previously on this issue and, while the interviews were in progress, there seemed a realistic likelihood of war breaking out again. However, as it turned out, I did not feel in any way that this created tension between myself and the Indian participants as my identity as a South Asian (‘one of us’ as opposed to ‘the other’), in addition to sharing the same ethnic background, language and many aspects of culture on top of the fact that there was no political discussions, overcame any potential problems.

The concept of ethnically matching the researcher with participants so as to overcome potential pitfalls in terms of cultural and linguistic competence has been the subject of vigorous debate. The dangers of conducting insider research have been highlighted in terms of researcher ‘marginalisation’ and the overlooking of transferable skills that

good researchers have in their ability to transcend gender, religion and ethnicity (See for example: Gunaratnam, 2003; Rhodes, 1994). It seems to be the general consensus that, on the whole, ethnically matching the interviewer with the participant is conducive to rich data collection (Bhopal, 2010; O'Donnell *et al.*, 2004; Sawyer *et al.*, 1995) as participants will generally be more open about culture and ethnicity, or religious issues, to someone who they can believe will understand. Gunaratnam (2003), in her discussions of ethnic matching in an interview setting, suggests it leads to a greater sense of confidence and discussing experiences than would be the case where the researcher is from a different ethnic background to the participant. Other writers such as Bridges (2001), for example, in his article '*The ethics of outsider research*' has been critical of the view that 'disempowered groups' are better researched by insiders. Vociferous in his opinion that 'outsider research' can contribute to the better understanding of the researcher, of the community engaged in the research and of the wider community, his view is not without merit as is the point made by Dyson (1987), who has suggested how a perception of being an outsider by parents of mentally handicapped children meant that those parents then gave a more explicit account of their world and did not assume shared knowledge. As such, I was aware of the issues of 'tacit' knowledge and as a result women were encouraged to give detailed explanations of points discussed as, although I may have understood what they meant, many people reading the research may not.

Another criticism of insider research is the question of the quality and accuracy of the data collected and whether the data is 'sanitised' due to the fact that it may also prove to



be difficult for participants to criticise aspects of their culture or religion, or even to admit to deviance from accepted behaviours or cultural norms (Elam & Fenton, 2003; Song & Parker, 1995), to a researcher from a similar background. As a researcher, I was aware of this potential partiality, especially when the issues of termination were being discussed. Although commentators such as Modell et al (2000a) illustrate that Pakistani women are not averse to terminations if necessary, such actions involve moral, religious and cultural dilemmas and, as such, they may impinge upon the possibility of open dialogue between researcher and researched. Although a more detailed discussion of participants' perceptions of termination will be included in a subsequent chapter, it is important to highlight at this point that I was aware of the possibility that some Muslim women might give culturally acceptable answers regarding very sensitive issues such as the religious and cultural unacceptability of terminations (Haw, 1996). This is illustrated by the following participant, whose strongly expressed views against termination may represent a desire to reinforce perceived cultural norms in front of a researcher regarded as an insider:

*“This is from God, who are we to refuse it? We will not terminate. You know in Islam it is a very big sin to terminate, so we refused that test. We said we will take whatever God gives us.”*

(Participant 21. Pakistani Muslim age 26. Married, not at-risk couple. Two children, trait status unknown.)

Insider research can be perceived as a double-edged sword: it can help or hinder progress, especially in sensitive subjects. In this case, it helped in that I was perceived as an apni (one of us) and time was willingly made available for interviews. The

potential flip-side of this ‘insider-ness’ is the risk of coercion to potential participants, as they may feel they cannot refuse one of their own and thus feel obliged to take part in such studies (an issue discussed in an earlier part of this chapter). As a result I remained alert for verbal and non-verbal signs of participant disquiet; questions were invited and, as previously indicated, consent was confirmed again prior to the interviews being conducted and after instances where interviews were paused due to the upsetting nature of the subject being discussed. My identity as a South Asian woman was, in many cases, the paramount factor in facilitating access to many of the participants. This fact has also been illustrated by AngLygate (1996) when she wrote about her experiences in accessing the Chinese community. It was only when her part-identity as a woman of Chinese origin became clear that she was allowed unrestricted access and, indeed, acceptance into her target community

*“I specifically declared to be Chinese and her subsequent response to me changed dramatically. ‘Oh! If you are Chinese, you are most welcome.’”*

Ang-Lygate (1996: 54)

There are, however, degrees of ‘insiderness’. By the very fact of being a researcher, I was somewhat removed from those I interviewed by my level of education and employment ((Bridges, 1997). However, when Bangladeshi women were interviewed with the aid of an interpreter, I became an ‘outsider within’ due to the fact that although my gender, South Asian identity and religion were important factors in establishing rapport, dialectic and national differences, in addition to the presence of the interpreter, led to an element of distance in the interview setting.

## **5.6 Conclusion**

In summary, the focus of this chapter has been to discuss the various intricacies of the data collection phase. This chapter has illustrated the fact that recruitment of minority ethnic groups can be challenging with added difficulties for insider researchers. I have also discussed aspects of data collection and the mediating factors that either affect the quality and quantity of the data collected or access to the setting. In addition, I have highlighted my obligations as a researcher which led me to forfeit opportunities for data collection in order to preserve the participant's safety and privacy or in order not to be responsible for informing a woman of her status as a carrier in the first place. The post 9/11 and 7/7 environment has resulted in concern and disquiet amongst the Muslim population, which has led to an environment of suspicion and mistrust of people perceived to be outsiders and those asking questions. However, many participants took part in the study and shared their experiences with the researcher on the basis of the researcher's own identity as a British Muslim woman. In the case of the Indian and Bangladeshi participants, the researcher's multiple identities of being a Muslim and a South Asian overcame any potential issues. In the next chapter, I will begin to examine in more detail what the participants were prepared to share with the researcher in the interviews.

## **CHAPTER SIX: NEGOTIATING MEANINGS: THE BETA THALASSAEMIA TRAIT AND 'THE SELF'**

### **6.1 Introduction**

South Asian cultures on the whole tend to adhere to different values than those of Western societies (Goodwin, 1999; Triandis, 2001). Where Western societies (the US for example) place strong emphasis on the individual in terms of rights, self expression and freedom, South Asian cultures, by contrast, focus on the individual's responsibility to their family and society. Identity within South Asian culture is informed by the individual's role within their family and extended family. Their sense of duty and responsibility to their families, in most cases, takes precedence over their individual expressions. Such differences in views and belief systems may lead to a different set of behaviours and social constructs in negotiating overall identities and may result in tensions when trying to integrate in a society where individual expression is encouraged.

This chapter will describe some of the life experiences of South Asian women who have  $\beta$ TT (beta-thalassaemia trait) - some of whom are mothers of  $\beta$ TM (beta-thalassaemia Major) children. This chapter will also explore how women with a potentially discreditable attribute (the  $\beta$ TT, which is concealable but can be intentionally or unintentionally revealed, leading to stigma, (Goffman, 1963), make meaning of this attribute and then, in turn, how they negotiate their identities in terms of the values that the cultures in which they live deem important. Traditional values, such as those of protecting the family honour and of childbearing, are tied up with the general discourses

of femininity, gender and power in the wider society. In recognition of this, the concept of ‘identity’ that will be used here is situated within the social and personal contexts of daily life which, in turn, mould life experiences (Fearon, 1999) in this case, the experience of living with the trait. Social or personal identity is influenced by the attributes which are valued among a particular group or culture. Within the context of the  $\beta$ TT, a woman’s identity would be determined by, among other things, the ability to produce (healthy) children and producing a child with a disability, such as  $\beta$ TM, would be potentially stigmatising for her and her family. The quotes presented in this chapter are taken from the interviews with these women.

## **6.2 Negotiating identities and avoiding stigma**

The overarching theme of this study is to try and understand the impact of a genetic trait upon South Asian women and how they manage their identities to avoid being stigmatised. Goffman (1963:5) defined the effects of stigma as an “*attribute that is deeply discrediting*” and can potentially reduce the bearer of a particular attribute “*from a whole and usual person to a tainted, discounted one.*” The stigma theory has been further developed by Falk (2001), who went on to identify stigma as ‘existential’ (attributes over which a person has no control) or ‘achieved’ (which, as the term suggests, the individual contributed heavily towards achieving that attribute). Jacoby et al (2005), along with Goffman, Falk and others, suggested that individuals with potentially stigmatising attributes are thus labelled and, as a consequence, are awarded lower status and discriminated against since they do not ‘fit’ into the roles assigned to them by society. The result is that the stigmatised person is not accepted or accorded

the respect, rights and regard of his or her peers and is thus disqualified from full social acceptance. Drawing on these ideas, it could be assumed that, if a person has been labelled and thus stigmatised due to the consequences of an illness, for example, he or she will typically try to 'normalise' their interaction within society by learning the culturally appropriate 'sick role' which Parsons (1951) suggests. By actively seeking a medical resolution of the illness that may have resulted in stigma, an affected person could be said to have fulfilled their moral obligations to themselves and society at large by acting as the 'good patient' and doing everything in their power to aid recovery, including consulting expert medical help and complying with any treatment regimes. However, Parson's theory is problematic in the context of the current research, since it is only relevant for acute, short-term illnesses and not long-term chronic illnesses or even genetic traits.

Although, medically, a trait is not viewed as a disease, it is still governed by the realms of medicine and, thus, can be viewed in the same way as a disease. That is, the person is not 'whole' due to the fact that they carry a genetic condition which may have medical implications.

Chattopandhyay (2006) explains that in the Indian subcontinent, carrying the  $\beta$ TT may impact on socio-cultural dynamics in that purity of blood is such a valued anthropological concept in both lineage and reproductive contexts. Therefore, by its very existence, the  $\beta$ TT mutation is perceived to be corrupting the blood. As a result, the implications for the affected woman and her sense of self-worth can be seen to flow from societal concerns about blood being pure and untainted so that she can produce

‘pure’ (healthy) offspring. Indeed, her self-worth may be compromised if she herself internalises the devaluation that society attaches to tainted blood or a medical condition (Goffman, 1963). Therefore, in the case of the  $\beta$ TT where a woman is not *physically* sick, the trait can be perceived as being a *social* illness as it has massive implications for the concept of following prescribed roles, such as attaining a good marriage and motherhood - more importantly, a mother of healthy children. In such situations, affected individuals may be better able (dependent on their personal circumstances and resources at their disposal) to strategically manage information that they divulge about themselves, for example, women with  $\beta$ TT would try to minimise the genetic condition or hide it by what Goffman (1963) terms as selective disclosure strategies.

In denying the potential existence of the trait to oneself, the following participant describes how this is made easier by the invisible nature of a trait:

*“The main thing I see as myself not having any physical disability or even em....you know internally I don’t have any disability, you know. I’m quite a healthy person, that’s the main thing, I get on okay, I’m quite fit you know Alhamdulillah [praise to God]”*

(Participant 1, Muslim Pakistani aged 31. No children with Thalassaemia major.)

Due to the invisible nature of the genetic trait, women may be able to hide it from their families more easily than if this condition had visible signs. This is particularly important during transitional stages of their life such as marriage. Newly married South Asian women can occupy a complex position in their husband’s household. As Bhopal (1998:488) succinctly asserts *“It is the daughter-in-law who has the lowest position in the home of her husband and his family. If and when she gives birth to sons, her status*

*may increase and she too may maintain an acceptable and legitimate place in the family of her husband.”*

Giving birth to ‘healthy’ children gives women a certain sense of importance and status within her husband’s families. These women are in a better position than those who are unable to conceive or give birth to healthy children (Riessman, 2002).

In circumstances where the women were either living with their own parents or in nuclear families (n=36), they were able to selectively disclose the trait and minimise potential stigma from their in-laws. This was because their in-laws were not living with them, which made it easier for them to withhold this knowledge from them. Non-disclosure of this information played a fundamental role in the management of a potentially spoiled identity (Goffman, 1963) as asserted by the following participant:

*“Actually, here I live with my mum and dad and my in-laws are in Pakistan so they didn’t need to know anything really.”*

(Participant 3, Pakistani Muslim aged 25. At-risk couple.)

The disclosure of a genetic trait to in-laws, for example, can be a worrying dilemma for some women, as illustrated in the following quote (conducted with the aid of an interpreter):

*“...she’s scared is if her in-laws know, they might think something of it”.*

(Participant 34. Bangladeshi Muslim age 19. Married, not at-risk couple. One child, trait status unknown.)



As can be seen, this woman feared the repercussions of her in-laws finding out about her trait.

Higher socio-economic status may, in some circumstances, act as a protective buffer against criticisms by in-laws (Jadhav *et al.*, 2007). The following participant, for example, felt a degree of protection due to the socio-economic superiority of her own family in comparison to her husband's family:

*"I didn't have to face this problem because I am from a prominent family and they may have been afraid to ask me. It's maybe that they're afraid of asking me in case I become angry, I don't know."*

(Participant 4, Bangladeshi Muslim aged 50. One major child, one carrier.)

Generally speaking, the participants who did discuss the trait did it in a way that avoided disclosing the hereditary implications of the trait. Instead, they focused on the physical manifestations of the trait such as the anaemia-like symptoms, which can be culturally more acceptable as this condition is very common among females in certain parts of the world including the Indian subcontinent (Galloway *et al.*, 2002). There are high levels of anaemia in South Asian women living in Britain (Chapple, 1998), which may be due to religious and cultural restrictions on certain foods resulting in a lack of iron in the diet (Chapple, 1998) and, as such, it is viewed as an accepted part of womanhood as demonstrated by the following participants who chose not to give a detailed explanation of their trait:

*“They've asked what is that, I just say something about blood cells, red blood that's it and then they tell me to eat properly, that's it.”*

(Participant 21, Pakistani Muslim aged 26. No affected children.)

*“To them [in-laws] I'm just anaemic, more than anybody else, that's how they see it.”*

(Participant 2. Pakistani Muslim aged 32. Married, not at-risk couple. One child, disabled and trait.)

The above quotes illustrate that some women were more comfortable partially disclosing the acceptable and common symptoms of the trait than talking about its hereditary nature.

Another acceptable way of partially disclosing the trait was by drawing attention to other physical manifestations of it, such as musculoskeletal pain i.e. joint pains, which, like anaemia, is common amongst South Asians resident in the UK (Njobvu *et al.*, 1999). In this study it was found that participants seemed more comfortable talking about common symptoms such as those mentioned, rather than the serious genetic consequences:

*“Well I think that a common symptom of carriers, I don't know about the other patients, but I noticed all the patients who are carriers, they have this one common fact that everybody gets like a right leg aching or both the legs aching.”*

(Participant 42, Indian Hindu aged 45. None known affected children.)

It is worth noting that a potential drawback of associating joint pains and anaemia to their trait is that these women may not seek to rule out other possible causes. In

retrospect, this issue could have been further explored but at this stage it suffices to say that this may have been a potential issue arising from the way these women managed the knowledge of their trait.

It is understandable why the women in this study found it easier to talk about the ‘acceptable’ face of the  $\beta$ TT since the potentially devastating genetic consequences can devalue their status amongst their husband’s family. At this point I will briefly explain why South Asians women’s lives may be so intertwined with their cultural perceptions of how they should act and behave.

In the context of the current research, the South Asian female ‘self’ is socially constructed and regulated. South Asian women are cognisant of their place within society, the life they lead, their relationships with others as well as attitudes towards them. Despite having produced four female prime ministers (Indira Ghandi, Benazir Bhutto, Khaleda Zia and Sheikh Hasina), South Asian society remains a contradiction in that, in general, it expects females to fulfil gendered expectations and become ‘good’ daughters and wives (Bhui *et al.*, 2007). For example, Bhopal (1999) asserts that women in South Asian cultures are assigned the guardians of family honour (*izzat*) and, thus, this role becomes intertwined with the institutions of marriage and family which are very strong and lend support to each other, so much so that the ‘success’ of a woman’s marriage is judged by her ability to bear healthy, especially male, children as stated by the following patient:

*“When I had my daughter, my in-laws gave me a lot of worry because I had a girl, then when I was pregnant again, I prayed to God to give me a*

*son, so that I can have some respect in that house. He was fine when he was born, everybody was happy.”*

(Participant 40, Indian Sikh female aged 40. Three children; one major and two carriers.)

As the above quote indicates, although this participant was living in England, even then she was subject to her in-laws’ disapproval by the act of giving birth to a daughter. Bhopal (1998) also explains how cultural and religious values in the Indian subcontinent, for example, have resulted in the second class status of women in society. Their mobility, work, self-esteem and self-image, indeed their self-worth and identity, seem to depend upon the judgments of the male members of a patriarchal society, which is then reflected in the diaspora. South Asian women can be hostages to cultural practices, such as the dowry system, which renders them a burden and restricts their self-expression and choices in life (Fouberg *et al.*, 2009; Menski, 1998). Consequently, such are the inequalities faced by women that they are subject to other people’s judgements and something like a medical condition may ‘taint’ and sever their prospects of a good marriage

The importance that South Asian society places on adhering to conventional and expected roles within families is so immense that participants have spoken about knowing ‘at-risk’ couples who have been under so much pressure to have children that they have not considered the serious consequences of giving birth to a  $\beta$ TM child:

*“I think they were so desperate to have a child that at that stage they you know didn’t think...”*

(Participant 11, Pakistani Muslim aged 37. None known affected children)

Pro-natalist in nature, South Asian societies appear to attach a lot of significance to fertility and procreation and the inability to have children has therefore been classed as a ‘social death’ (Riessman, 2000) and can cause broader problems for women in terms of social stigma, economic hardship, social isolation and even violence. Bennet and Manderson (2003), in their study of infertility among South Asian women, reported that an inability to produce a child renders women a liability and, as such, jeopardises both their ‘selves’ and their social and physical security, giving examples of women who were abandoned and subjected to violence and abuse and, as a result, many women will go to great lengths to avoid the shame and humiliation of their fertility coming into question and stigma associated with it (Domar & Gordon, 2010).

Stigma by association, or ‘courtesy stigma’ - a stigma acquired as a result of being related to a person with a stigma (Goffman, 1963) and the fear of such, may lead families to hide the trait from their extended family and the community in general so as not to impact the chances of a good marriage for other (especially female) family members, as was asserted by the following participant:

*“They [parents of  $\beta$ TT daughters] probably worry about their daughter's condition becoming public and then having difficulty in marrying her off.”*

(Participant 7, Pakistani Muslim aged 25. Pregnant with first child.)

In families where the trait was disclosed, some women commented upon the whole family becoming affected and symbolically tainted by the presence of the trait. Unmarried children, especially females, would then be considered damaged by proxy,

which would have implications for the planning of future arranged marriages, a point illustrated by the following participant:

*“They don’t tell anyone, this is why it’s a social problem. They think that their daughters will never get married if we tell.”*

(Participant 4, Bangladeshi Muslim aged 50. One major child, one carrier.)

Awareness of such information within the family circle can also lead to a form of stigmatisation. Link and Phelan in their work on conceptualising stigma (2001) discuss the boundaries created through labelling certain family members as having what is perceived as a negative attribute. This was displayed in this study whereby some participants commented upon internal conflicts and politics within extended families and, in some cases, they would distance themselves from carriers or those affected by  $\beta$ TM by separating “us” from “them” (the deviant and tainted), which then reinforces social stereotypes, as emphasised by this participant who had a  $\beta$ TM brother in law:

*“Yes, but they have that in their family, they’ve had it for a long time. But we didn’t know what kind of illness thalassaemia was, God forbid”.*

(Participant 10, Pakistani Muslim aged 40. No known affected children.)

The subconscious cues that this participant gave whilst discussing her husband’s brother’s  $\beta$ TM made it obvious to me that there were tensions between this participant and her in-laws. The subtle changes in her voice and her facial expressions when discussing the illness hinted that she was labelling her in-laws as tainted and, by downplaying her own lack of symptoms and the impact of  $\beta$ TT on her, she was

verifying her own (healthy) superiority. Such perceptions can have implications for traditional cultural practices such as consanguinity. If family members discover an illness which can be passed onto the future generations then it might discourage inter-familial marriage. This contradicts the claim made by Darr (1990) that consanguinity may act as a protection against stigma. Darr argued that consanguinity may act as a buffer in that families with a trait would not stigmatise themselves but, as the above participant illustrates, that stigma can occur within such families.

Even out with consanguinity, ascertaining the health status of a prospective partner is not considered an acceptable social practice - a point noted by one participant:

*“Well you can't [ask the prospective family whether they have the trait], being an Asian you know, you cannot, it's all arranged you know so you cannot ask the other people because they will think 'oh they've got something wrong with them' straight away. You know then you'll have a marriage refusal and that sort of thing so you don't talk about these sorts of things. I wish it would be more open but you cannot do that so you know it was like on luck”.*

(Participant 42, Indian Hindu aged 45. No known affected children.)

As the above quote illustrates, asking about health-related issues may be considered as insensitive as well as suspicious.

However, some families may request testing prospective partners as a result of their own  $\beta$ TT. Even then, that information may still be withheld, as was described by the following participant:

*“...but my brother that’s younger than me he em..... got married 2 years ago to our cousin and my mother said to her father (uncle) that have her checked. And they just ignored it. So they both got married, he had the trait. So he has the trait, she has the trait... Last year in August, em...I think she must have been 3 months (pregnant) in August and she was diagnosed....She went for the amnio and they told her that her baby had thalassaemia major”*

(Participant 2, Pakistani Muslim aged 32. One child with trait.)

In the above case, the implications of the request for testing being ignored appear to be that the participant’s sister-in-law carried  $\beta$ TT and that a child with  $\beta$ TM was conceived, leading to late termination and causing severe distress for the entire family. While the issue of termination will be discussed in greater detail in the next chapter, it is sufficient to say here that there is diversity in opinions within families as to the termination of an ‘abnormal’ foetus and while this participant’s sister-in-law underwent a termination, many would not.

Families withholding medical information for fear of their daughters remaining unmarried may slowly dissipate over time with acculturation and the changing nature of marriage (Angelo, 1997). Although the traditional preferred method amongst the South Asian communities is still the ‘arranged’ or introduced marriage, marriages in which partners freely choose each other are slowly becoming accepted in many parts of South Asian cultures, especially in the diaspora (Hussain, 2005). As already seen, arranged marriages can be heavily laden with the need to perform within cultural norms and expectations. In comparison, marriages that are not arranged by families and in which couples choose each other are conducive to a more open dialogue, particularly about sensitive issues. As the following participant asserts, this type of marriage arrangement



may mean that the role of parents or of the extended family become peripheral in the context of choosing a healthy partner with whom to have children:

*“P: ...I actually knew before I was married that I was carrying that and I actually told my husband that “look this is what I've got, you need to go and get yourself checked out because if you are a carrier, then obviously our kids will be affected...” so I was really open about the fact. So that's what he done, he had a full blood test done.....*

*R: And your family would have been okay with that?*

*P: Yeah, cos it was my choice (whispers)*

*R: Right*

*P: It wasn't an arranged marriage so, that was okay.”*

(Participant 8, Pakistani Muslim, aged 21. Pregnant with first child.)

While the arranged marriage reflected the majority experience among the research participants in this study, there were women who had chosen their own spouses (n=4), although this does in some cases have the potential to cause conflict within families. The above participant, when whispering that her marriage was her choice, was reflecting the generational issues of honour, shame and personal choice. Her marriage choice may have continued to cause consternation between herself and her parents. She was aware that her situation was perhaps considered deviating from the norm within her family or community and may have felt apprehensive in discussing her marital background when her mother was within close proximity in another room.

Where couples choose their own partners, they might relegate the importance of certain issues, such as medical information, as highlighted by the following quote:

*“When you fall in love with them... its... you don’t care what they are, you don’t care what they’ve gone through, you don’t care who they are?”*

(Participant 18, Indian Muslim aged 32. Three children, trait status unknown.)

To illustrate the diversity of experiences within South Asian communities, even where participants chose their own partners, the issue of whether (or not) to divulge the trait and the potential reaction did cause some concern. One participant pointed out the delicate balancing of divulging trait knowledge to a prospective partner:

*“Well, its very difficult.....em..... now if you're going to marry somebody or you're planning on having children and if you love somebody, the first thing you have to say before you fall in love with them is that “I've got thalassaemia and you have to be checked” I mean at the end of the day, what do you do?”*

(Participant 2. Pakistani Muslim aged 32. Married, not at-risk couple. One child, disabled and trait.)

Irrespective of cultural backgrounds and ethnicity, this illustrates some of the dilemmas and difficulties faced by people with a genetic condition such as  $\beta$ TT.

The following participant summed up how disclosure of her trait may have been received had it been revealed at the time she was getting married:

*“I know if anybody's to say anything, if anybody's to talk in ours [culture] it's a stigma and you carry it even when you're going to get fixed up or anything... “oh she's got that blood thing, she's got that blood*

*thing". And to be honest, nobody needs to know anything, but say your partner when you're married you know what I mean?"*

(Participant 18, Indian Muslim aged 32. Three children, trait status unknown.)

This quote illustrates the participant's recognition that anything viewed as 'abnormal' or 'defective', even if it is 'hidden' such as in the blood, can cause stigma, which can then have far-reaching implications such as for herself, her partner, her family and within the wider community.

For some of these women, disclosing sensitive information to partners proved to be challenging and a strain on their marriage. In the following section, some of these difficulties are discussed.

In this study, the majority of women (n=25) only found out about their  $\beta$ TT when they had their antenatal blood tests carried out. They were then expected to begin the task of negotiating partner testing, which would then require explanations to husbands and potentially risk the negative consequences described previously such as being stigmatised and blamed. However, according to the majority of women who were in this particular situation, their partners accepted this information in a matter of fact way. As this study did not include their partners I was unable to corroborate this assertion by these women. By virtue of being a Pakistani I belong to the same community as these women and thus am aware of the complexities within South Asian families, as well for the desire to save face i.e. to preserve their self-respect and not disclose any domestic tension to the researcher, as I belonged to their community. It is worth mentioning here that, although there were many advantages of being a researcher belonging to the same

community as my respondents, such as I could interview them in their first language and we shared tacit knowledge which helped the flow of the interview, the issue of saving face in front of me was a potential disadvantage.

Although women said that their husbands might be initially worried after being told about the trait, this worry would diminish if they were found to be clear of  $\beta$ TT, as highlighted by the following participant:

*“First he [husband] was really shocked and then he was saying things like what’s going to happen? He’s never heard of thalassaemia, so he was very worried. When he found out about [clear test result], after that he was okay.”*

(Participant 30. Bangladeshi Muslim age 25. Married, not at-risk couple. One child, trait status unknown.)

These participants generally felt that their husband were amenable to blood tests, however some husbands were reluctant, as discussed by the following participant:

*“R: Did he understand why he would need to go in for blood tests?”*

*P: Yeah, he did understand that, but he wasn’t quite happy. He was saying, what he said was ‘I’ve already got less blood; I’m not going to give more blood.’”*

(Participant 3. Pakistani Muslim aged 25. Consanguineous married, at-risk couple. One child, trait status unknown.)

Thus women were not only were dealing with the issue of trait diagnosis themselves but had to manage their husband’s reactions and concerns.

So far I have described some of the challenges and difficulties that women face in managing the knowledge of the trait themselves, how they then negotiate this knowledge within their family and how they also have to deal with their husband's reactions and concerns. Now I will go onto talk about the experiences of living with and caring for a child who has  $\beta$ TM.

#### **6.4 The experience of caring for a child with thalassaemia major**

This study highlighted a marked contrast between women who had an affected child and those who did not in terms of quality of life, socio-cultural and religious implications and the meanings attributed to carrying  $\beta$ TT. This, in turn, had implications for the way the mothers perceived themselves as well as how they felt others (family, community and society) perceived them. This study found that women who were not part of an 'at-risk' couple tended to relegate the trait to a less dominant, almost non-existent position within the context of everyday life. On the contrary, women who were caring for a child with  $\beta$ TM (n=6), faced a different set of challenges. The challenges that arise from caring for a chronically ill or disabled child transcend cultural and ethnic differences and are experiences shared by parent carers (Boerner *et al.*, 2004). South Asian women in Britain can be additionally vulnerable due to the geographical separation of support systems such as kin, marginalisation, communication issues and socio-economic deprivation (Hatton *et al.*, 2003). Vulnerability and stress can also be increased where, due to the nature of the illness, hospitalisation is a common occurrence, as can be the case with  $\beta$ TM complications or even when blood transfusions are given on a frequent basis. Sapountzi-Krepia *et al.* (2006) documented that

frequent hospital admissions for chelation therapy was associated with increased maternal stress and this was confirmed by one of the mothers who recalled:

*“You’ve got this little baby who’s been poked and prodded and he’s crying. It was absolutely horrendous.”*

(Participant 41, Indian Hindu aged 52. One child, thalassaemia major.)

Mothers of children with a disability have many roles that they need to fulfil, which may require a complex balancing of caring for the ill child, caring for any additional children and undertaking familial responsibilities (Nahalla & FitzGerald, 2003), as well as the psychological consequences of dealing with their child’s illness. The psychological stresses of caring for a child with  $\beta$ TM are indicated by the following participant, who had feelings of being overwhelmed by her responsibilities and concerns for her child:

*“My life is on hold for that child, I constantly worry about him. I am still trying to find a match [for bone marrow transplant]. I pray to God he becomes well. I get up in the morning, take him to school, collect him and I don’t ever leave him alone, I’m afraid of what will happen.”*

(Participant 40. Indian Sikh age 40. Married at-risk couple. Three children, one major, two carriers.)

In addition to nurturing and being the main caregiver to their child, some women in this study also had to deal with the anger of their ill child, as highlighted in the following example of a participant whose child was 17, and the corresponding blame levelled at her:

*“He [son] says to me that you're the bitch who's kept me alive. He refuses counselling. If he had a good day he could just about cope with taking the pump at night but if everything was going badly, it was like a domino effect, there is no way I'm taking the physical pain on top of the emotional pain. I tried so hard to understand and to help him, I wish I could take the thalassaemia instead of him so that I could cope with it better. Even now I feel grief and helplessness.”*

(Participant 41, Indian Hindu aged 52. One child, thalassaemia major.)

The helplessness that this mother felt as a result of her son's reluctance to subcutaneously chelate may not be as pronounced today as it was seven years ago as options of oral or a combination of oral and subcutaneous chelation is available. In addition, community matrons play a fundamental role in clinically and psychologically supporting both the affected individual and their families, which helps to overcome many such issues that sufferers and their families may have (Dossa, 2010).

Some women discussed the added stresses arising from being the main caregiver to their disabled child whereas their husbands were very much peripheral, as the following participant describes:

*“And so the ways he handles it is to... he just buries himself in his work which actually in its own way has taken a very major toll on the marriage. Whereas we might have been getting closer and spending more time with each other, because he's always evading the problems that have come along and the difficulties of that major...the way he's dealt with it is to distance himself from the problem and leaving me to cope with and pick up the pieces and because in some ways it's felt like being a one parent family really if I'm honest about it.”*

(Participant 41, Indian Hindu aged 52. One child, thalassaemia major.)

The lack of support from partners greatly impacted upon the mothers, especially when they were also dealing with conflict from the extended family regarding having a  $\beta$ TM child. The 'Western ideal' of the husband and wife as one cohesive social unit did not seem to apply to many of the families in this study. A number of women commented that not only were they dealing with hostility from the extended family as a result of having a disabled child, but were specifically targeted for blame while the father's role in reproduction was ignored or minimised. In addition to hostility from family, they felt let down by the lack of support from their husbands - as one woman put it:

*"I've always had problems, you cope with them [in-laws] as best as you can, but when your husband turns against you, it's difficult to cope with."*

(Participant 40, Indian Sikh female aged 40. Three children; one major and two carriers.)

One participant recounted how hostility was directed at the *child* rather than the parents, with the child being viewed as being responsible for the restricted lifestyle of the parents, especially for reducing the earning potential of the mother:

*"...she's [mother in law] sitting there making all these catty bitchy remarks you should give him up like my niece did and all the rest of it. I mean I just couldn't take it..." "how much is he costing you per year to stay in?"*

(Participant 41, Indian Hindu aged 52. One child, thalassaemia major.)

In general, the impact of having a chronically ill child was made more challenging by the lack of support they experienced from their husbands.



According to Williams *et al* (2002) the home is for most people a place of safety and security. However, for some women in this study who had children with BTT, their homes had become a complete contradiction to the ideal of the marital home as a place of security where the illness of their affected child could be managed. This then had a detrimental effect on the wellbeing of the women, especially those who did not have support systems that they could draw upon. Lloyd and Hall (1993), in verifying this, suggested that women who lack strong familial social support systems are three times more likely to experience abuse and stress. This was illustrated by the following participant:

*“He [husband] said it was my fault; I gave birth to an ill child. So much has happened to me because of this child, the in-laws would beat me up because of my son, even when he got his injections and my son would cry, they would come after me, I’ve had a very hard life. I used to pray to God not to give anyone kids or if he was going to, to make them healthy. Ever since I’ve come to this country I’ve never been happy, I didn’t even know what married life was supposed to be like.”*

(Participant 40, Indian Sikh female aged 40. Three children; one major and two carriers.)

As can be seen, this woman recalled many years of emotional and physical abuse that she had experienced at the hands of both her husband and his family primarily due to her son’s  $\beta$ TM. Her hardship was further exacerbated due to her isolation in a different country without the support of her own family:

There is growing recognition that, even now, South Asian parents with disabled children have issues accessing support services even with the advent of support mechanisms for the self-management of long term conditions (Croot *et al.*, 2008) and

this was apparent in this study, which was undertaken prior to the implementation of such initiatives. Many times women commented upon the lack of support available to them as parents of chronically ill children. The impact upon emotional, psychological and physical health was immense, especially where women were subject to abuse. In addition, the mothers' perceptions of how difficult it was to care for their child led to depression. Coping strategies included a reliance on alcohol, as illustrated by the following participant:

*“I had a social worker coming in saying hello how are you, and that’s about it, how’s X, how’s the little one? Just a hello chat, it didn’t do me any good at all it was a waste of money and time, the whole thing, it was very sweet but totally ineffective...and em.. I started to develop a drink problem...thinking about it now, X was about 2 or 3 years old and he was very able to communicate, he was very articulate, by this age he was making sentences and I think he was compensating for... you know he was a very intelligent kid, still is. And he was talking and talking and talking and one day the social worker popped in and I said would you like a drink and what I meant was can I make you a cup of tea, it was 10 o’clock in the morning and my son walked up to the cocktail cabinet and he actually offered her, can I get you sherry? This is a three year old kid. And she said WHAT? I said no! Because he had seen his mum going up to the cabinet during the daytime and having a sherry just to stop the pain in my head. I was actually gulping glasses of sherry, to kill the pain in my mind, just to knock myself out, I was on tranquilisers all the time, all this sort of nonsense was going on, and I realised when my kid said that; I said hello am I becoming an alcoholic?”*

(Participant 41, Indian Hindu aged 52. One child, thalassaemia major)

Due to the lack of psychological and emotional support services available to women, the above example highlights how the absence of support may force women to turn to other options to help them deal with the stress and trauma of their situations. Although in the present day, community matrons and Expert Patient Programmes are designed to

offer support to families. However, women who are vulnerable and isolated may not be able to access these services so it is even more imperative that there are culturally-appropriate support mechanisms in place for them. I will now move on to discuss how some women in this study tried to make sense of the cause of their child's illness, which is a typical thought process that those dealing with chronic illness can go through (Bury, 2002)

## **6.5 Perceived aetiology of $\beta$ TM**

In many cases, having a child with  $\beta$ TM led to the mothers trying to attribute cause for their children's  $\beta$ TM. This was especially instigated, in some instances, by the reaction of close family members, including the spouse and extended family members. This study saw some mothers either blaming themselves for their child's disease or, as recalled in the following excerpt, being blamed for their child's health outcome:

*"I had problems in the house, they all blamed me for my son's condition saying you gave birth to an ill child, there is no other problem, but the doctors had said that there is something in the parents which is why your son is ill. But my in-laws just blamed me... they found a scapegoat in me and left it at that."*

(Participant 40, Indian Sikh female aged 40. Three children; one major and two carriers.)

Although none of the mothers with thalassaemia major children regarded their child as cursed, they did feel a sense of individual responsibility, either as a result of accusations from family members for producing a chronically ill child, or simply because they gave birth to them. One such mother tried to make as much sense of her child's illness as she

could within her limited knowledge of BTT and felt that the father was just as responsible. However, although he was a trained physician, his cultural beliefs were still paramount in his outlook on illness and disease (Kleinman & Benson, 2006) and, according to the participant; he denied any responsibility for their thalassaemia child, which he viewed as an assault on his virility and masculinity:

*“P: My husband denied any responsibility. But there was no question after we had blood tests again in Italy; we were all tested for possible bone marrow transplant.*

*R: So you're saying that your husband denied he had anything to do with your son being a major?*

*P: Yes.*

*R: Even though he was a doctor?*

*P: Yes. First he wouldn't believe it. He said it had nothing to do with his blood, it wasn't his fault. It was all my fault.”*

(Participant 4, Bangladeshi Muslim aged 50. Four children, one major.)

By absolving any (shared) responsibility for the child's genetic condition, the father in the above excerpt is reinforcing the gender power dynamics within the household by displacing blame to the (powerless) mother and, at the same time, ensuring his identity of 'father' and 'healthy male' remains intact (Holroyd, 2003; Vijesh & Sukumaran, 2007).

## **6.6 Religion as a coping strategy**

The psychosocial impact of having a chronically ill child leads to many parents developing appropriate coping strategies which, as Atkin & Ahmad (2000a:59) argue, can include ‘embracing the medical model’ in order to make sense of the illness. In contrast, this study has illustrated a stronger tendency to draw on religion as a coping strategy, while incorporating some aspects of the medical model.

Religion formed a pivotal part of the women’s everyday lives across age, ethnicity and socio-economic background where meaning was given to the trait and its impact on personal life (including the management of pregnancy) within the context of religious beliefs and values. In addition, Dein and Stygall (1997) and Tarakeshwar et al (2006) suggest the importance of the role of religion in the management of illness, and this was reflected in the way that religion was used to manage the experience of living with the knowledge of having the  $\beta$ TT by the mothers in this study. The religious affiliations of the participants in this research were Hindu, Sikh and Muslim, and their religious beliefs and values were used not only as coping strategies, but also to give a deeper understanding and meaning to the issues experienced by them.

For Hindu and Sikh participants, the perception of karma was used both as a coping strategy (Awasthi & Mishra, 2007) and an explanation of disease and illness within the family. Adverse life experiences were thought to be the result of sins committed in previous lives and people had to atone for this by sacrifice and good actions to break free of this cycle (Hinnells & Porter, 1999). This is aptly illustrated in the excerpt

below in which this Hindu participant had given meaning to her son's illness by attaching a religious, personal and pragmatic narrative to her son's thalassaemia major:

*"I'm one of these people who count my blessings every day and thank God he was born, if he was going to have that major, he was destined to have it and we were destined to have him which is what I believe, faith does a lot of fate, I'm Hindu you know so I believe in these things, I believe in karmic deaths that you pay for your past life and in some ways. Although I feel this, my husband says it is a cross we have to bear. I used to really take exception in that, I don't call him a cross that you're bearing. It used to really upset me. I mean I'm doing all the carrying of the burden if you call it a burden and he's not my burden, he's my baby".*

(Participant 41. Indian Hindu aged 52. One child thalassaemia major.)

The above participant's perceptions of her husband's lack of understanding and empathy regarding their son's illness were clearly a source of frustration for her. Similarly, one Sikh mother understood her suffering of having a thalassaemia major child as a consequence for previous sins, albeit she was the only participant to question why God would make her suffer as she felt she had done nothing to deserve her situation:

*"I never would have committed a sin, I don't know what sins I'm paying for now. God knows what I've done to face this".*

(Participant 40, Indian Sikh female aged 40. Three children; one major and two carriers.)

For some Muslims, the earthly life is merely a transitory and illusionary phase (Puchalski *et al.*, 2004). Suffering may be viewed by many Muslims as a test from God

and a way of attaining Heaven. The narrative of being spiritually tested was evident in this study, as the following patient illustrates:

*“He keeps saying that Allah has sent all illness for a reason, to test us...”*

(Participant 29, Pakistani Muslim aged 28. Four children, one thalassaemia major.)

Although the concept of suffering and tests from God were a larger part of the personal repertoire of women who had ill children, such as those illustrated above, it seemed that many of these views were ‘second hand’ in that, as the above excerpt illustrates, the participant seems to repeat her husband’s understanding of the illness as a test. There could be many reasons for this: either the participant’s own level of understanding about the concepts of genetics, DNA and illness were basic at best, or they did not want to discuss/face their feelings, especially in front of a researcher who shared some of their cultural and religious insights (Naples, 1997). Given the limited resources and time in which to conduct this study it was not possible to explore the experiences and views of the respondents’ partners. However, respondents’ accounts highlighted the significance of engaging with their partners’ accounts, which highlights the importance of doing this in future studies of this nature.

While all of the women used religion as a coping mechanism in various ways, the Muslim participants seemed to be more immersed in the practices of religious teachings. There was a sense, especially among the Muslim participants, that if God was going to test them, God would help them cope with whatever he gave them:

*“All these problems are given to us by God and we should face them, God gives us these problems but He also has a cure for every disease”*

(Participant 19, Pakistani Muslim aged 27. Two children, one major.)

This participant was relaying not only a belief but an actual saying of the Prophet Mohammed, who said that Allah sends down both disease and cure. For every disease He provides a cure. Not only is this proverb used as a basis of hope for a resolution, but beliefs such as these also act as props for coping (Adbullah, 2003). The ‘flip side’ of this belief may be that, although hope and prayer can be a very powerful coping strategy, it may also mean that health messages are not absorbed effectively because some people may be too reliant on this hope as a method to resolve issues that may impact them.

The belief that there was a treatment was an integral belief among many of the participants, regardless of religious background. This then promoted utilisation of traditional South Asian therapies, such as alternative or complementary medicine, but this was used alongside religious beliefs and practices, as indicated below:

*“My mum thinks if she prays hard enough it will go away and that kind of thing you know. I mean my mum tried a lot before she didn’t understand what thalassaemia was because she (X – participant’s sister) was the first child that had this problem you know because for how many generations nobody knew anything about it so they used to take X to India, she was about 3 or 4 years old and try all these homeopathic medication and all that, that when that didn’t work then mum took her to all these religious pilgrimages and other things so they wasted a lot of time and money basically trying to cure something they didn’t know about.”*

(Participant 42, Indian Hindu aged 45. None known affected children.)



Although this participant is trying to make sense of the way her mother was coping with her daughter's disability, she also feels that such therapies are unlikely to work and therefore her sibling will have to continue conventional therapy such as blood transfusion and iron chelation. This affirms Reed's study (2000) involving South Asian women and their experiences with diabetes, where the women were likely to try traditional remedies as well as Western ones to control their diabetes but, in some instances, where the condition was severe, Western medicine gained precedence. This may be partially explained by acculturation as well as levels of education. Overall, however, the theme of fatalism was a frequently occurring phenomenon in this study and the next chapter will look at its impact on the utilisation and understanding of the screening process.

## **6.6 Conclusion**

In conclusion, this chapter focused on how women who carry the trait negotiated and managed their identities within socio-cultural and religious contexts to avoid being stigmatised. I have also discussed how it is not only women who are managing their identities but their families play a major role in determining how much disclosure is acceptable which, in turn, influences how they are perceived by their potential or actual in-laws. Having the trait and potentially producing an unhealthy newborn has huge ramifications for how women perceive themselves and the implications for how they may be treated if they were blamed for giving birth to an 'unhealthy' newborn. This chapter has also shown the diversity of, and the cultural shifts taking place within, these communities in terms of marriage and family dynamics which impact on how and when

trait information is disclosed and the stigma associated with it. Women who had children with  $\beta$ TM described the difficulties and challenges associated with having a chronically ill child, including the lack of support and the stigma that she was somehow to blame. Finally, while religion plays a dominant role in many South Asian households, the conflicting narratives of “I’m trying to be a good Hindu or Sikh or Muslim” and “why me?” are not restricted to South Asians alone but the common thread here is that religious beliefs played a pivotal role in their everyday coping strategies as they lived with the consequences of their genetic traits in managing their child’s illness.

In contrast to the assumptions of health care professionals that genetic knowledge will be understood and acted upon in a ‘rational’ manner in making marital and reproductive decisions, in the present study culture, religion, experience of thalassaemia major, level of education and socio-economic demographics all played an integral role in the meanings that the women constructed as a result of their trait.

Stigma was a deep concern for many of these women at multiple stages of their lives, from when they discovered they had this trait through to the prospect of entering a suitable marriage, to then falling pregnant and disclosing trait information to their families and finally giving birth to and coping with a child with this devastating illness. Stigma can have far-reaching consequences not just for the person in question but for their entire family.

## **CHAPTER SEVEN: DIAGNOSIS OF THE BETA-THALASSAEMIA TRAIT AND ITS PRACTICAL IMPLICATIONS**

### **7.1 Introduction**

The previous chapter focused on how women managed the knowledge of a potentially discreditable attribute - the  $\beta$ TM - and the strategies they utilised to negotiate their identities and avoid becoming stigmatised. In addition, I examined the impact the  $\beta$ TT had on their everyday lives especially for those who had children with thalassaemia major.

This chapter will continue to explore the overarching theme of managing the trait to prevent stigma but will also examine the dynamics of the actual screening process itself. The chapter will ascertain the factors that interplay with the trait diagnosis such as age, personal circumstances, consanguinity and religious belief. I will then discuss the various ways in which these women ascertained that they were carriers. Finally, I will examine aspects of what I have conceptualised as 'active' and 'passive' fatalism in relation to how South Asian women are perceived by health professionals.

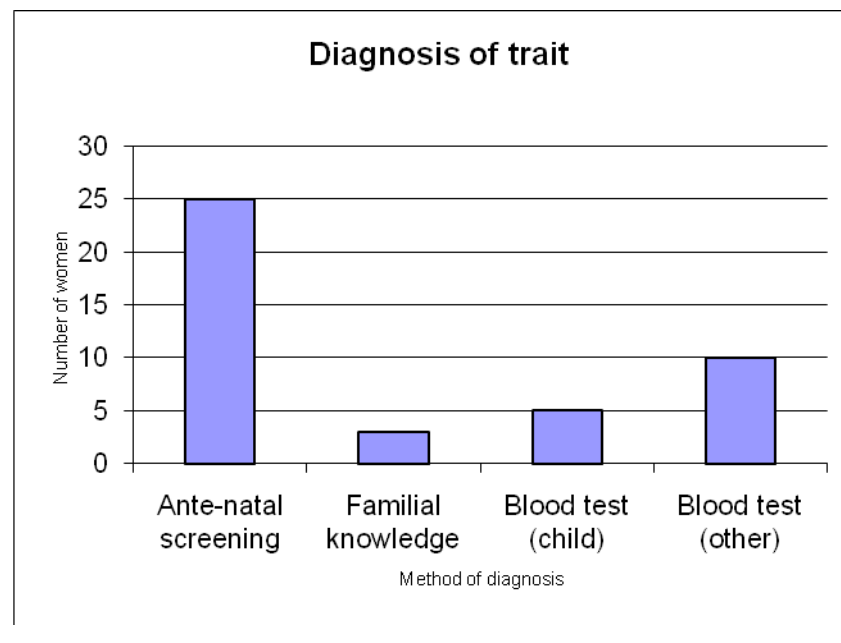
### **7.2 Diagnosing the beta-thalassaemia trait**

There have been various attempts by health professionals and the government to raise the profile of beta-thalassaemia amongst at-risk communities through, for example, the media, medical journals (Lakhani, 1999) and through community events such as a mela (carnival) by nurse specialists and the UK Thalassaemia Society. However, given this publicity of  $\beta$ TT, the majority of the participants in this study had never heard of the

term thalassaemia prior to diagnosis. This then suggests that general awareness of the condition was low in these affected communities (Anionwu & Atkin, 2001; Dyson *et al.*, 1993c), at least up until 2003, the point at which most of the data for this study were collected.

Discovery of  $\beta$ TT in this sample typically occurred as a result of blood tests undertaken for a variety of reasons, including testing for unexplained medical symptoms among children (n=5) or the participants themselves during adolescence (n=10), as well as the antenatal screening process (n=25). Knowledge of the presence of the trait within families affected by  $\beta$ TM children was also a common factor in motivating participants to get tested for the trait (n=3). Figure 11 graphically illustrates the reported mode of diagnosis for the study sample.

**Figure 11: Methods of trait diagnosis**



### **7.2.1 Tests to diagnose unexplained symptoms**

Ten women became aware of their carrier status as a result of blood tests, usually when they were children or young adults, for unexplained medical symptoms such as acne and constant tiredness. Test results were typically sent to the GP where participants were diagnosed with  $\beta$ TT and prescribed a course of iron supplements. The misdiagnosis of the small red blood cells of a person with  $\beta$ TT as a sign of iron-deficient anaemia, resulting in the prescribing of iron supplements, was a common feature in this study with almost all women having had at least one course especially during pregnancies. Although many GPs gave their patients iron supplements, the general consensus these days is that this course of action is contraindicated as this type of anaemia does not respond to supplements and it risks iron accumulation around major organs (Scott-Ricci & Kyle, 2008). Furthermore, it could be construed as a sign

that the GPs themselves knew very little about the clinical pathology of the trait. However, regardless of the clinical value of prescribing iron supplements, many of the women who took them felt a beneficial effect, as illustrated by the following participant:

*“...after she prescribed me with the tablets ... after that I realised that I had more energy in me as well that I wasn’t also very tired....”*

(Participant 28. Pakistani Muslim age 28. Married, not at-risk couple. Three children, trait status unknown.)

A common experience with those who were diagnosed during adolescence was the very limited information the participants received from their GPs about the potential impact of the trait, especially at various junctures in their lives, as the participant illustrates below:

*“I was about 17 , 17 or 18 em...complaining of tiredness quite a bit, went to my GP and she said to me you look like you're anaemic em...the tiredness, gave me iron tablets and said let's go in for blood tests, went for a blood test em. And then she called me in, it must have been I don't know 6 weeks later or so and said its just to let you know that you are slightly anaemic but they have actually found out that you are actually beta-thalassaemia trait so you're a carrier and it's just for you to be aware of that for the future for when you have children”.*

(Participant 6. Pakistani Muslim age 30. Consanguineous marriage, not at-risk couple. Two children, trait status unknown..)

Although the GP did hint at the potential impact of the trait, the participant felt that very little effort had been made to direct her to further information or to follow-up within a couple of years. Another participant felt that her GP seemed to brush aside the potential impact of her carrier status in terms of marriage and reproduction, as indicated below:

*“...cos it went on for a while, he [GP] sent me for a blood test...because he thought... simply for my acne but when this blood test came back he told me when I went for the results that everything else was fine but this is what they've picked up. Something called beta-thalassaemia trait in the blood test which... so I asked him about it and blah blah...Basically he wasn't.... sort of like it's not really important whatever but it's nothing that affects me now he said”.*

(Participant 18. Indian Muslim age 32. Married, not at-risk couple. Three children, trait status unknown.)

Atkin and Ahmad (1998) have previously highlighted the inability of GPs to clearly communicate the implications of the test results to the women and to anticipate future issues in choosing potential marriage partners that this might draw them into. This study showed that there was a need for recognition by GPs that follow-up appointments may be required when these children reach 18 or 20 years of age, for example, when the question of marriage may begin to be considered. Due to this resulting lack of follow-up, the women in question in this study thought no more about their trait and thus, when they married, partner testing was not even considered, as one participant explains in the following excerpt:

*“P: When they were checking, I was 18. I was at [name] Hospital and then they got us all in to check our blood and that's when we found out that you know we were all carriers and they were thinking of taking bone marrow from my younger brother or me, but nothing came of it.*

*R: How did that affect you at that age knowing that you were a carrier?*

*P: It didn't bother me. It didn't bother my brothers either because at that time, basically we really didn't know how it happened like you know we didn't have much knowledge of it I mean we knew that our sister's got thalassaemia, but how she got it we had no idea, we didn't know that two partners got to be carriers so it didn't bother any of us and it didn't affect any of our lives as such because we didn't have any symptoms or*

*anything. I think we were all anaemic but you know, it didn't affect our lives, I think we got used to that. You know like today, my blood count goes down to 8 but ...*

*R: Were you offered counselling or given any information about what it means to be a thalassaemia carrier?*

*P: No, none. No one even told us you know if you got married you've got to make sure your partner is not a carrier or anything, I mean that's why we didn't worry, it didn't bother us."*

(Participant 42. Indian Hindu age 45. Divorced, not at-risk couple. Three children, status unknown.)

The above quote shows that this participant felt that the diagnosis and the discussion that ensued around it with her GP did not emphasise enough the seriousness of this condition. This perception that health care providers lack awareness of the incidence (and impact) of  $\beta$ TM among South Asians (Atkin *et al.*, 1998) was reinforced by the following patient who, throughout the interview, remained angry about her suffering as a result of the limited knowledge of beta- thalassaemia among front-line health care providers:

*"...I'm horrified that GPs, some of them even today do not know about thalassaemia, that's what makes me so angry, it makes me really livid at times. I think its criminal not to know about genetic diseases, just because they're ethnic minority things."*

(Participant 41. Indian Hindu age 52. Married at-risk couple. One child, major.)

While this participant was recollecting events from the 1980s in terms of the discriminatory practices of health care provision for BME groups, more recent literature has suggested that this lack of adequate knowledge and provision may still be prevalent



today. In a study by Qureshi et al (2006), many GPs felt that they lacked the confidence to provide basic prenatal genetic advice to women at risk of hereditary disorders such as  $\beta$ TT and had even less confidence where both members of the couple had  $\beta$ TT. This gap in knowledge had implications for rapid referral to prenatal diagnostic services which would have given women adequate time to make important decisions in managing their pregnancies.

In addition, one participant recalled how, upon her diagnosis, she explicitly asked her GP about the potential consequences of the trait only to be told there was nothing to worry about:

*“I'd NEVER actually heard of thalassaemia before in my life and I didn't have a clue what it was, but when I asked her I said “will it affect me?” she said “it will not affect you in any way, you've got nothing to worry about for yourself”. So that sort of makes you feel better. You think well, there's nothing wrong with me, but not enough information into what it actually is about.”*

(Participant 6. Pakistani Muslim age 30. Consanguineous marriage, not at-risk couple. Two children, trait status unknown.)

The above excerpt also illustrates the impact of misleading information in certain situations such as marriage. The participant felt that her GP failed to inform her of the possible implications and seriousness of marrying a trait partner.

## **7.2.2 Familial knowledge**

In addition to discussion with their GPs, some women found out that they could potentially have this trait due to other family members having the trait and this

knowledge being openly discussed. In the present study, families who were aware of the trait by virtue of having affected family members tended to be slightly more open about discussing thalassaemia - at least within their immediate families. Yet this level of 'openness' did not in general extend to a discussion of the implications of the carrier status in terms of marriage and reproduction. Interestingly, the following participant did not seem to hesitate in disclosing her own trait status, which may, in part, be due to the respondent having attained a higher level of education (she is a pharmacist) as well as other members of her family being in the medical profession. As a medical issue, the trait tended to be a matter of open clinical discussion, at least with this participant:

*"P: It's always been with the family so...with my parents telling me.*

*R: When you were growing up with it, before you got married, did you ever think about the need for your husband to be tested?*

*P: Yes I did.*

*R: Where was he, did he come over from Pakistan?*

*P: No he lived here in this country, and he did have a blood test.*

*R: Before the marriage?*

*P: Yes."*

(Participant 11. Pakistani Muslim age 37. Married, not at-risk couple. Four children, trait status unknown.)

This arguably shows the effect of 'normalising' the trait and identity (Goffman, 1963) from an early age as part of the familial repertoire, making it acceptable to discuss issues openly and without the fear of possible stigmatisation. However this level of

openness was unusual and, for most of the women in this study, disclosure was laden with a fear of stigma.

It should also be mentioned that there were other circumstances where knowledge about the trait existed within families but it did not lead to a sense of openness. In the following case, disclosure was made in almost a casual manner and the information, once given, was kept dormant rather than being openly discussed to alleviate any concerns, as may happen in other areas of genetic risk such as cancer (van Oostrom *et al.*, 2007).

*“Okay, em I found out because my mum told me what I know, it was just in the conversation and she said oh you're a carrier by the way.”*

(Participant 43. Indian Hindu age 20. Single.)

This selective disclosing of the trait in terms of “oh you're a carrier by the way” without any apparent follow-up dialogue would suggest that the parents in this case were unaware of the possible connotations and implications of the trait and, thus, were unable to disseminate this information to their children. On the other hand, it may be that, as Shaw and Hurst (2008) imply, discussions about biological reproduction are considered embarrassing within a family setting. In any case, in the next chapter there will be a more detailed discussion of the practicalities of disclosing genetic information within families.

### 7.2.3 Diagnosis as a result of children's blood testing

Five women in this study only realised that they had the trait when their children were diagnosed with  $\beta$ TM as a result of blood tests for unexplained symptoms around the age of one year. These unexplained symptoms, such as failure to thrive, anaemia and problems with feeding, typically result when the child ceases production of foetal haemoglobin which, up until that age, had protected the baby from the severe disease (Decherney & Nathan, 2002). With profound anaemia, bouts of fever and diarrhoea as well as intestinal problems (Libby, 2008), parents become increasingly concerned about their children's health, as highlighted by this mother:

*“When he was 4 months old, he would never eat anything, he used to be very pale. The doctors checked him and his blood and said he has thalassaemia we'll have to give him blood. They then started his treatment”.*

(Participant 40. Indian Sikh age 40. Married at-risk couple. Three children, one major two carriers.)

In all five cases, concern about their children's health involved constant presentations to the GP and included being labelled as an overprotective parent or even a hypochondriac until a diagnosis was made. The following participant, in recollecting her experiences prior to her son's diagnosis, stated:

*“When he turned 6/7 months old, I started saying 'why is he losing his pinky colour and becoming pale-ish, you know I was a bit concerned because I was always looking out for that because I was like that you know? And my GP says to me that I was an overprotective mother, overanxious, and the neighbours used to say overanxious mother, my husband would say she's always clucking like a blooming hen, you*

*know, I'd get all these silly comments. My mother's instinct was warning me and nobody was taking any notice."*

(Participant 41. Indian Hindu age 52. Married at-risk couple. One child, major.)

The diagnosis of their child's illness typically came as a total shock, as many mothers had never heard of the disease and the prognosis was usually perceived as quite bleak – at least according to the mother's perspective. This mother recalled the severe shock of being told her son had  $\beta$ TM:

*"Never in my life had I even heard this word, absolutely ever. So it came as a total shock. I mean, I don't know, it was like a lightning bolt, I've had lightning fall quite close to me in my life, but that was far easier than what happened when I found out."*

(Participant 41. Indian Hindu age 52. Married at-risk couple. One child, major.)

This mother recounted how she was almost paralysed by the fear of the unknown when her son's thalassaemia major was diagnosed. She suggested that the shock was akin to being informed her son had a terminal illness, which in her mind was confirmed by the lifelong clinical interventions that he would require and the life-changing impact it would have for the whole family. This situation was, perhaps, exacerbated since the mother had received the diagnosis and prognosis as well as the treatment plans in the same meeting, which she had attended alone. These experiences could, in part, be due to the absence of adequate information and support needed to create effective coping strategies. This participant's experience also reflects findings by Taanila et al (1998), which recount similar parental experiences at the time of their child's diagnosis, such as fear and information overload.

#### 7.2.4 Diagnosis as a result of antenatal testing

In this study, the majority of women (n=25) were diagnosed as a result of their antenatal booking blood tests, in which blood was taken for routine testing of haemoglobin, blood type, infections and iron count, among other things.

Once a trait had been diagnosed, participants received a letter from their health care providers informing them of their trait status and requesting partner testing. Sending trait diagnosis by letter without any form of prior explanations during the time blood had been taken led to confusion and fear for many of these women, who did not understand what they had been diagnosed with, its implications and how it would affect their pregnancies as highlighted by the following participant:

*“My main concern was that I was pregnant at that time and I was worried for my baby really and how that would affect it”.*

(Participant 24. Indian Sikh age 25. Married, not at-risk couple. One child, trait status unknown.)

Although the Department of Health (1993) stated that screening programmes should offer the choice of testing to individuals, there was very little evidence in the study that the participants felt they had a proactive choice and, of this sample, only one woman (Participant 1) did not take up the offer of partner testing. Ahmed (2000a), in her doctoral study of the consent process among Pakistani women, suggested that, although there was a positive attitude towards testing by women who were carriers of the  $\beta$ TT, the majority of women in her study were tested by default during their booking visit. Similarly, all the women in this study were tested by default and were unaware they

could refuse screening. In addition, many felt that they were rushed through the process without being given the time to assimilate the information and to realise the meanings and implications of their carrier status, as illustrated in the following excerpts:

*“She [counsellor] told me I had what you said and I should get my husband tested quickly. I was really scared; I thought I had a bad disease like cancer or something.”*

(Participant 39. Indian Hindu age 30. Married, not at-risk couple. One child, trait status unknown.)

Another participant said:

*“She [counsellor] was just really worried at the time, because when we told her that we were related as well, she was saying that I have to go off for the results right now, with the tests and find out what you are and then she phoned me back in about two hours time to tell us. She was quite worried.”*

(Participant 9. Pakistani Muslim age 24. Consanguineous married, not at-risk couple. One child, status unknown.)

The latter patient had been diagnosed with the trait late in her pregnancy, thereby reducing the time span in which she could effectively manage her pregnancy. In this case, there was anxiety on both sides (i.e. the patient and the healthcare professional), although there seemed to be some dissonance as to the reason for this concern – the healthcare professional was perhaps aware of the impending time limit for decisions about termination for example, while the participant had concerns about her understanding of  $\beta$ TM and what it would mean for both her and her unborn child.

This disjointed communication between counsellors and patients has previously been investigated by Dyson (2005) who, in his study of sickle cell and thalassaemia counsellors, suggests that the interplay or dynamics of the screening process is conducted in a very stressful environment for both healthcare professionals and the patient - situations which can have the potential for miscommunication. Although the Standing Medical Advisory Committee (SMAC) guidance, *Report of the Working Party on Sickle Cell, Thalassaemia and Other Haemoglobinopathies* (1994), recommends that counselling be non-directive and given by staff specifically trained to do so, pragmatism seems to be the dominant factor in the dynamics of the counselling session. There may be a myriad of reasons behind this, for example counsellors have to explain the medical impact of  $\beta$ TM during the counselling process, which has the potential of causing distress among women given the short timeframe involved, as was suggested by one of the counsellors interviewed in this study:

*“Once the partners are screened, we then identify whether the couple are at risk and if they are at risk, then we inform them of that. Hopefully earlier on if we're seeing them for the first time... I do discuss pre-natal diagnosis if the result is positive “have you had any thoughts about pre-natal diagnosis?” explaining what it is etc... Often they've never even heard of it. So there's not really a lot of time for them to hear this diagnosis and think about what an earth they're going to do if they should be facing that situation”.*

(Counsellor 1, London-based in a high density South Asian area)

It is, therefore, not surprising that the ethos of non-directive counselling is viewed as a way to overcome potential biases and provide people with balanced information needed to manage pregnancies in a ‘neutral’ manner, enabling freedom of choice. The reality



of such ideals are, however, questioned by writers such as Williams et al (2002), who query whether the values of non-directiveness can actually be achieved in practice. Many counsellors come to sessions with their own views about termination and the management of pregnancies which may inadvertently become apparent during the counselling session – even on a subconscious level (Aksoy, 1998). The implications for the management of the possibly affected pregnancy will be discussed in more detail in a later section of this chapter. However, it is sufficient to say here that the counsellor's viewpoints are likely to influence the patient, even on a subconscious level, who may feel (unintentionally by the counsellor), pressurised to frame her decisions about pregnancy management accordingly.

The distress felt by patients as a result of the screening and counselling process was highlighted by the following participant when the potential impact of the trait was realised:

*“We went for the check up and the nurse..... she really worried me, the nurse, about the trait. Before that I wasn't really concerned about it”.*

(Participant 9. Pakistani Muslim age 24. Consanguineous married, not at-risk couple. One child, status unknown.)

The following participant felt she was being ‘steered’ along the process whereby information is divulged to women with the aim of following a medically prescribed outcome – that of terminating an affected pregnancy:

*“And there was a time when she [counsellor] says to me you know em... there is time... still time for termination of the baby you know, she says*

*we can do further tests to find out you know if that is the case you know, you can have an abortion or whatever. And I got angry and I said "sorry what God gives God gives" you know and who are we just to treat life like that?"*

(Participant 16. Pakistani Muslim age 20. Consanguineous marriage, at-risk couple. One child, possible major.)

An individual's decision to undergo testing and their response to the outcome of that test (including the decision to undergo prenatal tests) are influenced by many factors. Very often their own values, such as religious, personal and socio-cultural, will play a dominant role in decision making (Marteau & Croyle, 1998). It may also be the case that there are stereotypical assumptions on the part of healthcare providers. These assumptions seem to include ideas that South Asian, especially Muslim, women are passive, repressed and unable to assert their own will. These attitudes among healthcare professionals have been reported by Atkin and Ahmad (1998) and Bowler (1993a; 1993b) and they were reflected in this study by women's experiences of the medical encounter. One woman during her interview was quite vocal about the stereotypical perceptions of healthcare providers as she highlighted below:

*"I'm sure you know the stereotypes the white people have of us as well as the doctor-patient relationship and the husband-wife power relationship."*

(Participant 6. Pakistani Muslim age 30. Consanguineous marriage, not at-risk couple. Two children, trait status unknown.)

There were women in this study who were quite assertive in the decision-making process, who debunked these stereotypical assumptions especially with regard to genetic testing, as the following excerpt highlights:

*“P: I went home with sheets for my husband to take a blood test, I thought about it afterwards and then we decided em....you know.....not to go ahead with it cos even if he was...we were just preparing ourselves for the worst anyway inshallah because there is no guarantee of your child being born perfect anyway.*

*R: So whose decision was that not to go for your husband’s blood test?*

*P: My decision.*

*R: Your decision?*

*P: My husband's not bothered either way.”*

(Participant 1. Pakistani Muslim aged 23. Married, not at-risk couple. Two children, trait status unknown.)

While it may be the case that decision-making within families is a joint process, the above participant has shown that this is not always the case. The diversity of decision-making dynamics needs to be recognised by healthcare professionals, whose assumption that the spouse or extended family will dominate the decision-making process is not always correct. In addition, the perceived benefits and accuracy of these tests also play a major role in their uptake. Marteau and Croyle (1998) suggest that individual interest in undergoing testing is more strongly related to perceived rather than objective risk. The theoretical ideal that tests offer some type of safety net, in which their main purpose is to reduce unnecessary worry among those with a low risk while recognizing those at high risk of a genetic condition so as to promote preventive measures, is not always attained. The extent to which individuals feel uncertainty about their risk of a particular condition, their need for certainty, and the extent to which tests will provide that certainty, are each important in determining whether they undergo a particular genetic

test (Marteau and Croyle, 1998). In this study, there were some women who perceived that the risk of testing far outweighed any benefits to them. When questioned in depth as to *why* she felt the tests were not beneficial to her, one participant responded by asserting that scientific tests were not infallible and that they could not guarantee a healthy child:

*“You go through all that emotional stress not even 100% sure if our children would come out to be major carriers or whatever. I think that was the major factor in deciding not to go ahead.”*

(Participant 1. Pakistani Muslim aged 23. Married, not at-risk couple. Two children, trait status unknown.)

By focusing on antenatal screening for the  $\beta$ TT, health service professionals were seen as overlooking other potential problems that could occur in a pregnancy that may, from the patient’s perspective, be worse than  $\beta$ TT, or  $\beta$ TM, as this participant indicates:

*“Because either way our children could easily come out with some sort of handicap. Worrying about thalassaemia and they could come out you know being quite abnormal and that does happen.”*

(Participant 1. Pakistani Muslim aged 23. Married, not at-risk couple. Two children, trait status unknown.)

However, there needs to be a recognition that for women (n=3) who were able to assert independent decision-making, others (n=2) felt that they needed to involve their families, either because they valued their counsel or it was culturally unacceptable to deny family elders’ involvement in the decision-making process. This is reflective of the power dynamics and the limited autonomy of women within some South Asian families ‘back home’, which can be reflected in the diaspora, as highlighted by Shaw

(2000) and Ballard (1994), for example, who highlight the conflicting need to retain perceived values back home while trying to assimilate into the British culture. Screening decisions can, therefore, potentially be negotiated in any number of scenarios and not necessarily by a typically perceived scenario which involves delegating the decisions to family elders or the male spouse.

Women who had undergone antenatal screening in previous pregnancies (n=6) recalled receiving communication from clinics suggesting that those with new partners may like to undergo couple screening again, as relayed by the following participant:

*“During my second pregnancy there were no tests done because I think they looked at my previous notes. Then when I had my 3<sup>rd</sup> one after 8 years, then I got a letter from the hospital again which I really feel is good in one way so at least you know like after 8 years they've still got my records and they wrote to me you know like the gore [white people] keep changing partners and things like that. I had that kind of letter if you have changed your partner or anything you've got to have another test done, but if it's the same partner there's nothing to worry about.”*

(Participant 5. Pakistani Muslim age 38. Married within beradari, not at-risk couple. Four children; trait status unknown.)

Although this participant felt amused at what she perceived was the assumption that her own cultural practices may reflect the white majority population's culture, nevertheless she felt reassured that her medical records were being actively accessed upon perceived need.

## 7.4 Managing 'at-risk' pregnancies

For the majority of women (n=25), the antenatal screening process passed without further considerations, For example, the participant who had undergone much anxiety during the screening process admitted that, afterwards, the  $\beta$ TT had become a non-issue:

*"I don't think it was like a major thing, cos after I found out my husband was in the clear and it didn't affect my baby, I wasn't really bothered about it after that to be quite honest."*

(Participant 9. Pakistani Muslim age 24. Consanguineous married, not at-risk couple. One child., status unknown).

As indicated earlier, genetic counselling aims to provide patients who have a genetic risk with information about their condition and its potential impact to allow patients and their families to make an informed decision on how to manage a possibly affected pregnancy. However, the decision-making process does not occur in a vacuum since, as illustrated by Atkin et al (2008), women's attitudes towards prenatal diagnosis generally reflected their attitudes towards pregnancy management and termination, so women who did not believe in termination would not undergo prenatal diagnosis. This finding was evident in this study by the dynamics of decision-making of the at-risk couples (n=8). For instance, one participant refused to undergo the prenatal testing process and, although she admitted that she was worried, she adopted what might be perceived as a fatalist attitude in coping with the situation:

*"Yeah, we were a bit worried then, I mean if I am a carrier and so was he then there could be a chance the baby could be a carrier but still we*

*thought we're going to go ahead and have the child. We were worried but still we felt like keep our fingers crossed and hopefully everything will be fine."*

(Participant 3. Pakistani Muslim aged 25. Consanguineous married, at-risk couple. One child, trait status unknown.)

In the case of another participant, (participant 2), who drew on her own experiences of having a severely disabled son and the emotional impact of consequential medical interventions, encouraged her at risk sister-in-law to have a termination, as she later recounted:

*"I said look at me, I said that I can see the doctors poking needles into my son's arm, I can do that but can you do that for your child. Will you be able to do that to your child...I think she must have been 3 months (pregnant) in August and she was diagnosed. She went for the amnio and they told her that her baby had thalassaemia major... and then em... She had a termination".*

(Participant 2. Pakistani Muslim aged 32. Married, not at-risk couple. One child, disabled and trait).

As there will be a detailed discussion in the next chapter on the perceptions and understandings of genetic risk, including the actual dynamics of the communication process, this chapter will focus on how women perceived the available options presented to them in the event of further testing and a potentially affected pregnancy.

#### **7.4.1 Continuation of pregnancy**

There have been many studies that have analysed the factors which decide pregnancy management especially among South Asian women, including, for example, Ahmed et al (2006) and Atkin et al (2008). The dominant role of religious constructs in the

women's personal sphere was in many cases the deciding factor in the management of at-risk pregnancies (Atkin et al, 2008). This finding was reflected in the present study where religion was the dominant value influencing the way in which couples or women decided upon the particular outcome of a possibly affected pregnancy. One particular line of reasoning for deciding against termination was the fear of repercussions as a punishment from God for the crime of termination and this is illustrated by the comments of the participants below:

*"She said she doesn't feel it's a good thing to do because her view is like a child is a gift from God and getting rid of a child is like committing a crime against Allah, so she doesn't even want to think about that."*

(Participant 31. Bangladeshi Muslim age 21. Married, not at-risk couple. Two children, trait status unknown, speaking through an interpreter.)

*"Yes, this happened to me, they said we can do such a test on you to tell whether the child is disabled or healthy but I said 'no' we will take whatever we are given... This is from God, who are we to refuse it? We will not terminate. You know in Islam it is a very big sin to terminate, so we refused that test. We said we will take whatever God gives us"*

(Participant 21. Pakistani Muslim age 26. Married, not at-risk couple. Two children, trait status unknown.)

Again, this concept of a child being a gift from God was apparent in this participant's reasoning for refusing a termination. Also it is uncertain as to whether this participant was versed enough to know Islam permitted the termination of a foetus if it posed a threat to the more developed life of the mother as opposed to being against termination outright.



#### **7.4.2 Termination of affected pregnancies**

This study was carried out with 43 women with varying levels of English communication skills, of whom 8 were part of an at-risk couple. For these at-risk couples, this then, in various ways, gave rise to the issue of pregnancy management. With regard to termination, decisions made were within the boundaries of personal experience, information, religious and cultural perspectives, period of gestation and familial support. As mentioned earlier, termination of a pregnancy is disapproved of by almost all of the South Asian religions, and where it is allowed, for example, if the mother's life is in danger, it is governed by strict conditions such as gestational period. In Hinduism and Sikhism, the notion of karma and rebirth is important for many, as is maintaining the circular pattern of life, death and rebirth. The fundamental belief is that each person is repeatedly reborn so that his or her soul may be purified and ultimately join the divine cosmic consciousness (Coward & Sidhu, 2000). Although Islam generally forbids termination, some theological schools have allowed it if the mother's life is in danger or the foetus has a serious disorder and termination is undertaken within 120 days of gestation (prior to the ensoulment of the foetus). To overcome persistent resistance from anxious parties, fatwas have been issued in certain Islamic states such as Kuwait, Saudi Arabia and Iran, legitimising termination under certain circumstances (Ahmed et al, 2006). Although there is no equivalent ruling in Pakistan or even South Asia, Pakistani-based studies have shown the relative acceptability of prenatal screening and termination (Arif *et al.*, 2008) compared with this study sample. Shuhaib Ahmed and his colleagues (Ahmed *et al.*, 2000b), for example, found that 47 out of 58 affected couples in his study situated in Pakistan chose to terminate affected pregnancies. More

recent work carried out in Pakistan has reflected a greater awareness of thalassaemia and acquiescence towards local screening programmes (Ahmed *et al.*, 2000c; Baig *et al.*, 2006; Baig *et al.*, 2008), although attitudes towards termination varied across couples.

In contrast, this study's varied sample showed that, while the participants had undergone the antenatal screening process, there was much reported resistance towards prenatal testing and termination. The only exception, as cited earlier, was participant 2, who had encouraged her sister-in-law to undergo the process which led to the late termination of her affected pregnancy – possibly as a direct result of having a child with a disability herself. Generally, views against termination among women in this study sample were contradictory to those in studies undertaken by Modell *et al.* (2000a), who had observed that the rate in uptake of prenatal testing by British Pakistanis was 73% in her sample of 48 women in the first trimester, with 11 of 12 affected pregnancies being terminated, with the rate falling to 39% (11 of 28) in the second trimester, with 4 of 7 affected pregnancies being terminated (p337).

Although questions about the management of an affected pregnancy were retrospective, it became apparent during the interviews that those women who were not part of an at-risk couple and would therefore, at the very most, have a child with the trait, were the ones who developed hypothetical scenarios in which they would terminate an affected pregnancy. On the other hand, those women who were at risk felt (at that particular moment in time) that they would not terminate an affected pregnancy. The following

participant, who was not part of an at-risk couple, viewed the concept of ‘suffering’ as a pivotal reason for her decision to terminate an affected pregnancy, as illustrated below:

*“R: I had a test done and was told that it was okay (when pregnant with the second child).*

*R: If he had it as well then what would you have done?*

*P: I would have had an abortion.*

*R: Was this your decision or was the family involved as well?*

*P: It was my decision because it won’t be the family who suffers, I would have the problems.*

*R: Did your husband agree with you?*

*P: Yes he did.”*

*(Participant 19. Pakistani Muslim age 27. Married, not at-risk couple. Two children, trait status unknown.)*

Although the above participant centralised the notion of her own suffering as the pivotal factor in possibly terminating an affected pregnancy – a fact observed in a recent study by Ahmed et al (2008), the following participant viewed the suffering of the child as well as the couple’s own resultant suffering as a primary motive for termination. Her concept of ‘suffering’ may have included not only suffering in an emotional and physical context but may have also involved aspects of the financial burden of a chronic illness:

*“She said I myself do think that we both should be tested because I don’t want a child to be born that will suffer and make us suffer”.*

(Participant 17. Bangladeshi Muslim age 24. Married, not at-risk couple. One child, trait status unknown., speaking through interpreter.)

### 7.4.3 Values

In addition to religious beliefs, the decision on how to manage a pregnancy that may produce a child with  $\beta$ TM was also dependent on the personal values of the participants, which may or may not follow the biomedical model of medicine. Illich (1976) has argued that modern medicine has challenged what used to be a natural part of life, namely pain, illness and death, and changed it from a personal challenge to a technical one. This argument can be extended to reproductive technologies, where medicine has developed ‘technologies’ it sees as alleviating pain and suffering of both parents and child by providing enough relevant information to prevent the birth of a disabled child, for example. This view was echoed by the following participant who viewed the erosion of traditional family caring values as a result of both the dominance of the medical model and the impact of acculturation in terms of adopting modern white British lifestyles, including the reluctance to be burdened with illness.

*“To be honest you know our Asian race here the ones that are born here, you know are changing rapidly, they're becoming more like gore [white people] you know. They'll probably say yeah yeah, we've got to have an abortion but you know abortion is haram [prohibited] you know. You haven't got the right to terminate life, that one thing we get from Islam, but nowadays people think oh, if a baby has thalassaemia, blood transfusions or he'll be handicapped and we'll have to take him to hospital. You know, too much stress and too many problems, people will say, forget it, kill it. Nowadays our young generation you know, that's the type of mind they've got”*

(Participant 18. Indian Muslim age 32. Married, not at-risk couple. Three children, trait status unknown.)

For the above participant, the traditional view of accepting illness, pain and suffering as part of everyday life, rather than being seen as an inconvenience, had been lost. Perhaps this was in part due to the advent of screening technologies which allowed people to make such decisions. While this particular participant was younger than many of the other women in this sample, her views seem to reflect the concern among many older members in society of the erosion of traditional values and acculturation which, in her view, results in the dominance of the medical model of disability that sees people with disabilities as medical problems (Shakespeare & Watson, 2002). As a result, curing or managing illness or disability revolves around prevention or identification and treatment in order to allow people with disabilities to lead a more 'normal' life which revolves around the medical profession, who become the conduits through which this alleged 'normality' will be achieved (Oliver & Sapey, 1999). The above participant may have felt that the (Western) society, in which we live, has become so focused on the limiting aspects of disability that it fails to recognise the worth of each individual life.

## **7.5 The consanguinity debate and the implications for screening**

Eleven women in this study were part of a consanguineous marriage, while 2 had married within the beradari (extended kinship). For the purposes of this study, the meaning of consanguinity is based on using Shaw's (2001:315) definition, which encompasses the wide variety of relationships that form our understanding of the term. Thus, consanguinity can be defined as *"marriage with people 'of the same blood' (second cousins or closer relatives, i.e. first cousins once removed, first cousins, double first cousins, uncles and nieces, and aunts and nephews)." Cousin marriages are an*

integral part of Muslim communities especially and most recent estimates suggest that 80% of UK Pakistanis marry their relatives and approximately 55% of these are consanguineous first cousin marriages, with many couples also having related parents (Modell & Darr, 2002). Other studies have looked at the incidence of cousin marriages in Pakistan, where they found that approximately 60% of marriages in one particular sample were of a consanguineous nature (Hussain & Bittles, 1998). As such, this study reflected the high prevalence of consanguineous marriages among Pakistanis in that all of the consanguineous marriages, as well as those within the beradari, were among the Pakistani Muslim couples. With regard to South Asians, the whole pattern of marriage has tended to differ between the Pakistani and Indian communities. In their audit of haemoglobin disorders in the UK, Modell et al (1997) discussed at length the different politics and marriage patterns within these communities that impact recessive disorders.

Consanguinity has long been the focus of medical professionals when discussing poor birth outcomes. Discussions initiated especially by healthcare professionals tended to involve the practice of consanguinity as a way to map thalassaemia within the family or even as a way of apportioning cause for a child's illness (Atkin *et al.*, 1998). After a brief hiatus, the consanguinity debate has been reignited and is now being fuelled by non-medics, including opportunist MPs among others. Ms Ann Cryer, MP for Keighley (2005), recently compared consanguinity to other risk-taking and deviant practices such as drug and alcohol abuse and suggested that families who practice consanguinity need intense (policy) input to change their behaviours:

*“Are those families given the chance to make an informed decision with regard to family planning? Do they understand the risks that are involved in having children from a consanguineous marriage? Not only do we have to deal with the problem of illiteracy but we must tackle our own inhibitions and move away from political correctness. Anyone who seeks to excuse the passing on of terrible illness due to cultural traditions needs to know that that sort of culture is unacceptable in the twenty-first century”.*

The ‘exoticisation’ of cultures that practice consanguinity as the ‘deviant other’ has been reflected in discourse in both public and health care spheres. In turn, this attitude had aroused deeper suspicion, amongst especially Muslims, who view this as another attack on their way of life and as a covert method of edging them towards assimilation (Daar, 2009). Furthermore, this attitude focuses attention on the practices of the Muslim community itself as the basis for genetic problems rather than providing services that are culturally appropriate to them and meet their needs, such as couple counselling. This point was highlighted by Darr (2005) who suggested:

*“Its predominant focus on reporting perceptions of a social practice as problematic, rather than genetic advances that will allow families to make informed choices is a reflection of how the dominant culture continues to deal with minority ethnic health. Locating the cause and solution to minority health issues within the cultural practices of those communities is well-documented. This ongoing approach serves to shift responsibility for the resolution of health issues from policy makers to individuals and communities; it continues to alienate minority ethnic communities and hampers the process of devising responsive services for our multiethnic population”.*

The consanguinity debate was further exacerbated by the fallout of September 11<sup>th</sup>, after which the spotlight was on the cultural practices of Muslims generally, so much so that one participant in this study admitted that she did not disclose that she was part of a consanguineous relationship (a finding that was later confirmed by Shaw and Hurst

(2008) for fear of how this would be perceived in the wider community, especially the healthcare settings:

*“I’d just got married and everything em... you know we used to come across a lot of people... would fire an insult saying ‘married a first cousin’ type of thing and saying ‘oh God’. So I think we didn’t like to tell anyone really after that.”*

(Participant 33. Pakistani Muslim age 26. Consanguineous marriage, not at-risk couple. Two children, trait status unknown.)

Feeling the need to withhold relevant information for fear of censure has obvious implications in the healthcare setting, especially in the screening process, where consanguinity is an issue. However, in the face of public criticism, there is defiance in maintaining cultural practices that are long-established, as the following participant insisted:

*“In our society, marrying a cousin is nothing.....you know it happens all the time, you do...It happens, its not going to stop, I don’t think it’s going to stop for a very long time.”*

(Participant 6. Pakistani Muslim age 30. Consanguineous marriage, not at-risk couple. Two children, trait status unknown.)

However, what is salient was the amount of confusion about the risk factors associated with consanguinity amongst the women in this study which, in many cases, was perpetuated by the medical profession. The following participant confirmed this when she recalled how her consanguineous marriage was attributed as the sole cause for her son’s birth defects:



*“P: When my youngest son was born, he had kidney problems.*

*R: Kidney problems?*

*P: Yes and they said that because you’re cousins your child has defects.*

*R: So they said your child's problems were because you and your husband are cousins, this was your first son?*

*P: Yes.*

*R: What did they say?*

*P: Nothing, they didn’t check us or him.”*

(Participant 14. Pakistani Muslim age 35. Consanguineous marriage, not at-risk couple. Two children, daughter trait).

Ahmed et al (2002) have also highlighted the trend towards attributing consanguinity as the primary cause for a genetic abnormality. This was similarly reflected in the above scenario where it seems that, since the couple were cousins, the focus of the consultation was therefore on consanguinity. In addition, neither the child nor the parents were further investigated and an in-depth explanation of their child’s disease was not pursued by the clinician.

The issue of consanguinity remains a bone of contention within the Pakistani community – not least because the concept is itself poorly understood (Shaw & Hurst, 2008; 2009). As seen above, parents are told that their child’s illness is a direct consequence of their consanguineous marriage rather than the result of carrying a genetic trait. Indeed, as highlighted by Shaw and Hurst (2008), the consanguinity argument does not take into account that parents of children with genetic disorders such

as  $\beta$ TM are witnessing other consanguineous marriages producing unaffected children and other children with  $\beta$ TM born from non-consanguineous unions, as illustrated by the following statements, where the participants were discussing the impact of consanguinity:

*“That’s NOT true because the way I said my cousin who’s got beta-thalassaemia major, her father is my uncle and his wife is not related to us in any way whatsoever. In any way, she’s not related to us, so it’s like... it’s got nothing to do with cousins. And then, my husband’s close to me so...so close you can’t get closer than that and he’s not a carrier and I am.”*

(Participant 37. Pakistani Muslim age 26. Consanguineous marriage, not at-risk couple. Two children, trait status unknown.)

*“But then when you look at it deeper and you find out why, it’s not simply cos you’ve married your cousin it’s because they’re carriers and they’ve got things that run in the family.”*

(Participant 18. Indian Muslim age 32. Married, not at-risk couple. Three children, trait status unknown.)

This intense focus on cultural practices as the root cause of medical problems is, in itself, governed by colonial stereotyping (Bradby & Williams, 2006). The white majority population single out so called ‘deviant’ practices as an illustration of the unsophisticated ‘inferiority’ of certain minority populations, resulting in abnormal births. This belief has been refuted by Ahmad (1994:423) who, in questioning the data on consanguineous marriage and genetic defects/illness, argued that:

*“The consanguinity hypothesis is over-simplistic to explain the higher rates of perinatal mortality and congenital malformations among the Pakistani population. Its popularity rests less on its scientific merit and more on its convenience in shifting the blame onto supposedly deviant*

*cultures and marriage patterns and its fit with racist ideas of alienness and deviance.”*

Indeed, when considering conditions beyond beta-thalassaemia, the consanguinity hypothesis overlooks issues of socio-economic deprivation that may be responsible for many aspects of poor birth outcomes among Pakistani populations (Ahmad, 1994).

Although the data point to consanguinity as the preferred mode of marriage within certain parts of the Pakistani community (Shaw, 2003), the negative perception regarding consanguinity is not only inherent in Western societies. Although I was unable to locate documentary evidence, anecdotal evidence from my immersion in the Pakistani community suggests that the negativity associated with consanguineous marriages is becoming increasingly common within South Asian communities, especially within the Pakistani community in the UK, which was reflected by some of the Pakistani women in this study. This, in turn, is also being supported by the change in marriage patterns visible in the South Asian diaspora, such as the preference for ‘love marriages’ among the younger generation. It became apparent in the interviews that, although many of the women viewed the practice of consanguinity in a positive or even neutral way, there were some women who stigmatised consanguineous marriages as dysfunctional, as highlighted by the following participant:

*“They [the medical profession] keep telling us that cousins who marry keep having disabled children, but do our people stop and think? They’ll keep on doing it without a thought of their children...”*

(Participant 21. Pakistani Muslim age 26. Married, not at-risk couple. Two children, trait status unknown.)

This negative perception of consanguinity may have arisen from perceived medical implications and suggests that the women who have begun to resist such practices may be more influenced by medical discourse and, perhaps, even a higher level of acculturation than those who pursued the consanguinity route. However, further research is needed to explore this.

Another participant recollected her personal experience with a disabled niece when discussing her negativity towards consanguinity:

*“You know how we say you shouldn't marry your cousins...You know my sister has married a cousin and their daughter doesn't talk, she's five years old and she still doesn't talk”*

(Participant 20. Pakistani Muslim age 34. Consanguineous marriage, not at-risk couple. Three children, trait status unknown.)

What is interesting in this case is that the participant who voiced this sentiment about consanguinity is herself part of such a relationship. While she may have followed her family's wishes in agreeing to a cousin marriage, she may have been voicing her uncertainty with regard to this practice by reflecting on Western medical discourse and the impact that consanguinity may have.

As this section has highlighted, consanguinity has become an issue not only within the wider society but within South Asian communities as well. It would be interesting to ascertain future perceptions of consanguinity within populations that traditionally practice this, who have become acculturated or, as a result of policy initiatives, are not able to bring spouses from overseas as they may have previously done.

## 7.6 Fatalism: conjecture and reality

The previous chapter introduced concepts of fatalism with regard to the meanings of the  $\beta$ TT. As an extension of that debate, this section will continue to develop ideas of fatalism but within the context of healthcare professionals' perceptions of preventing and managing at-risk pregnancies. As suggested in the previous chapter, some healthcare providers have assumed that Muslims are especially, by virtue of their submission to the will of God, fatalistic and, as a result, are not inclined to undertake proactive decision-making in the treatment of an affected pregnancy (Ahmed *et al.*, 2000b). This study highlighted the diverse practices that may be construed as passive fatalism or active fatalism as well as considering participants whose repertoire included the proactive management of the illness and of the  $\beta$ TT.

It is a common misconception by healthcare professionals that Muslims believe in fate and that in itself leads to a passive approach to healthcare (Mir, 2005). The danger of these kinds of assumptions is that, while some Muslims may passively accept providence and demonstrate fatalist behaviour, others will actively try to become responsible Muslims by demonstrating a greater adherence to certain aspects of their faith (Mir, 2005).

As with any complex issue, there is a myriad of actions and beliefs associated with both fate and fatalism. This study provided examples of both 'active fatalism' in which the participants recognised the importance of personal responsibility but, nonetheless,

accepted the ultimate role of Providence (participant 1), and ‘passive fatalism’, whereby the participants adopted a passive attitude of leaving their fate to God (participant 3).

Although the use of religious constructs as a tool for decision-making is one that has been devalued by health professionals, this study has shown that such constructs are very much valued by Muslims, especially in decision-making processes, as illustrated by the following participant:

*“I thought about it afterwards you know.....performed istikhara, so I thought 'okay' you know, inshallah [God willing], it was the right decision [not to go for partner testing].”*

(Participant 1. Pakistani Muslim aged 23. Married , not at-risk couple. Two children, trait status unknown.)

The Istikhara (or Salat-I-Istkhara as it is better known) is an intense prayer for guidance and is often used for help in making important decisions. By preferring to seek guidance from God and showing awareness of the fallibility of science, the above participant was not necessarily being fatalistic but, in this case, ‘marrying’ two distinct threads of knowledge into one that made sense to her, as she further clarified:

*“And we're not just relying on Allah, well alhamdulillah, relying on Allah but even if I did go ahead with my husband with my partner's blood to see if he is a carrier, if it did come out to be..... You go through all that emotional stress not even 100% sure if our children would come out to be major carriers or whatever. I think that was the major factor in deciding not to go ahead with any more and inshallah, just trusting. Because either way our children could easily come out with some sort of handicap.”*

(Participant 1. Pakistani Muslim aged 23. Married , not at-risk couple. Two children, trait status unknown.)

In addition, the assumption that the practice of consanguinity is an extension of fatalistic behaviour may be an established belief among many healthcare professionals (Atkin *et al.*, 1998). While this chapter has highlighted examples of women being informed that their child's disability was a direct result of a consanguineous marriage, it seems that any form of behaviour not adhering to the values and principles of the biomedical model of proactive prevention of illness and personal responsibility is in danger of being assumed to result from a fatalistic tendency, without any in-depth probing as to the cause behind a reluctance to undertake a particular course of action. One such example arose when a participant divulged that she had refused a Chronic Villus Sampling (CVS) procedure. If healthcare professionals had probed her motives for refusing (which they did not, perhaps viewing the patient's non-compliance as fatalist behaviour), they would have found that the woman's refusal was due to a more commonplace fear, as is illustrated in the dialogue below:

*R: Did you think about getting her tested before she was born, early on in the pregnancy?*

*P: They told me, I said no.*

*R: They told you she was a major?*

*P: No they told me to have a test.*

*R: Okay.*

*P: I said no.*

*R: You didn't want one?*

*P: No.*

*R: Why?*

*P: cos I didn't want to.*

*R: I'm not saying you were right or wrong, you know, I'm not judging you, I just want to know if you didn't want to have a test, the reason behind it.*

*P: Because I didn't want them to stick a needle through the stomach that's why.*

*R: Because of the needle?*

*P: Hmm...*

*R: Did it have anything to do with the fact that you're a Muslim; did that have anything to do with not wanting the test?*

*P: No, no.*

*R: Just the needle?*

*P: Yes."*

(Participant 15. Pakistani Muslim age 29. Consanguineous marriage, at-risk couple. Four children, daughter major, son trait.)

The simple notion of a fear of needles and pain clearly would not have been considered unless further sensitive exploration was done of the motives behind this participant's refusal. It is sufficient to say that, if the fear of needles had been discovered, the healthcare professional may have given the participant alternative options for the prenatal testing, such as trans-vaginal CVS, or suggested the use of anaesthetic creams to alleviate the participant's fear of pain resulting from the needle. This particular scenario also raises questions about the communication between the patient (whose



level of English was, at best, basic) and the healthcare professional, in addition to the involvement (or not) of an interpreter.

Furthermore, in demonstrating the diversity of beliefs and actions within this sample, another participant demonstrated a more proactive view:

*“You know how we say that it’s all from God, but there is such a thing called care.*

*You have to take some responsibility, you know, you know, when it’s a knife or anything lying there, you don’t stab yourself innit?”*

(Participant 5. Pakistani Muslim age 38. Married within beradari, not at-risk couple. Four children; trait status unknown.)

While in another instance, the participant reflected the stereotypical view held by healthcare providers that South Asians cannot be bothered to proactively manage their health:

*“No, no what I’m saying is that it’s just the Asian community attitude really; people just can’t be bothered really”*

(Participant 37. Pakistani Muslim age 26. Consanguineous marriage, not at-risk couple. Two children, trait status unknown.)

As demonstrated in this section, fatalism is a concept that can be viewed through different gazes; the clinical, the cultural and the religious. What may be considered as fatalistic practices by one section of the population may be viewed as more realistic and pragmatic actions by others whose experiences are grounded in their belief systems and

living realities, as evident among the mothers in this study in coping with the implications of their carrier status or of having a thalassaemia major child.

## **7.7 Conclusion**

This chapter has attempted to unravel and explore the many different, and possibly conflicting, experiences women may face during the antenatal and prenatal screening process. In doing so, I have attempted to bring together many narratives about how decisions were made which determined the management and outcome of a pregnancy within the worlds of women who were of different backgrounds and genetic status, that is, at-risk or not-at-risk couples. In addition, I also discussed the impact of cultural practices, such as consanguinity, in the screening process, as well as how some participants withheld potentially relevant information about consanguinity for fear of negativity from healthcare professionals. The chapter concluded with how religion is used as a decision-making tool in terms of pregnancy management and the screening process.

The next chapter will analyse the discourse of genetic counselling and the understandings of risk, as well as the dynamics involved in dissemination of genetic information and strategies for prevention.

## **CHAPTER EIGHT: THE ASSIMILATION AND DISSEMINATION OF GENETIC INFORMATION: IMPLICATIONS FOR SERVICE DELIVERY**

### **8.1 Introduction**

The two preceding chapters began by examining the impact of  $\beta$ TT on the participants in this study. In chapter six, I ascertained the strategies used by affected women to avoid or minimise stigma, which included ignoring or minimising the trait and its potential implications to the cultural values and roles that women are expected to adhere to. I also highlighted how the birth of a  $\beta$ TM child impacted on the participants on a personal and socio-cultural level. Chapter seven highlighted the different methods by which the participants discovered their trait status. It then focused on the antenatal screening process and the experiences of the participants and the issues they faced in relation to partner testing and the socio-cultural-religious dynamics involved in managing a potentially affected pregnancy. I also discussed concepts of consanguinity and fatalism and how these impacted upon the lives and decision-making processes of the participants.

This chapter will continue exploring the antenatal screening process but will focus on the delivery and assimilation of genetic information, how risk is communicated and presented to women, and their perceptions of the screening process. The chapter will then examine how women understood, utilised and disseminated genetic risk information within the context of managing a potentially discreditable attribute –  $\beta$ TT.

## 8.2 Understanding risk: making sense of genetic information

In order to understand the process of genetic counselling and what it hopes to achieve, it is perhaps pertinent at this point to consider the definition of genetic counselling. The simplest definition in terms of the ethos of the process is one that is conveyed by Harper (2004:3), who defines the process of genetic counselling as one where:

*“Patients or relatives at risk of a disorder that may be hereditary are advised of the consequences of the disorder, the probability of developing or transmitting it and the ways in which this may be prevented, avoided or ameliorated.”*

Given this definition, it is perhaps logical to surmise that genetic information is conveyed for a number of purposes. The Genetic Alliance, a US-based organisation providing information to patients and healthcare professionals, further elaborates that the function of genetic counselling is to:

- *“Increase the family’s understanding about a genetic disease, discuss options regarding disease management, and the risk/benefits of possible testing.*
- *Identify with the individual and family the psychosocial tools required to adjust to potential outcomes.*
- *Reduce the family’s anxiety.*
- *Educate people about their risk factors, informing them of the manifestations and prognosis of their potential disorder, enabling them to make informed decisions and empowering them to manage their lives in a pro-active manner.”*

Source: [http://geneticcounselling.hpage.com/process\\_of\\_genetic\\_counseling\\_71271736.html](http://geneticcounselling.hpage.com/process_of_genetic_counseling_71271736.html)

In order to achieve these aims, it is incumbent that those delivering genetic information understand the dynamics of how such information is processed and utilised, such as in the current study, where communication in the ‘technical’ language of the counselling process was an issue among South Asian communities, particularly since many women had limited English communication skills.

Aalfs et al (2007) described the delivery of hereditary genetics as the traditional domain of specialists specifically trained in human genetics, that is, clinical geneticists and genetic counsellors. However, this territorial control has somewhat diminished in recent times, allowing other health professionals such as non-genetic medical specialists, general practitioners, pharmacists, nurses and midwives to deliver information about genetic risk (Aalfs *et al.*, 2007). This diversity in healthcare professionals delivering genetic information was reflected in the present study. The majority of participants (n=25) were counselled by haemoglobinopathy nurse specialists, 5 by doctors and 13 by their GPs, reflecting the circumstances under which the trait was discovered. In other words, those who were found to be carriers as a result of their antenatal screening were then counselled by the nurse specialist. Women whose children were diagnosed with  $\beta$ TM were counselled by doctors and, finally, the GPs provided the diagnosis for those participants who discovered the trait at a much younger age through blood testing for unexplained symptoms, or who knew about the existence of the trait within their families and wanted to ascertain their own status.

Although genetic information was delivered by diverse specialists in the current study, the context and delivery of this information seemed to be consistent to the variety of ways in which Marteau (1995:18) describes the presentation of risk, for example, “*relative and absolute risks, numerical probabilities and proportions, and using a large number of verbal descriptors*”. Current literature also confirms the delivery of genetic information using formats which Marteau has described, examples of which are highlighted below:

*Verbal:*

There may be a natural disposition within the healthcare setting to convey risk information along the lines of ‘your chance of giving birth to a child with thalassaemia major is quite low or high’, dependent on whether the recipient is part of an at-risk couple or not. Although this format is fairly straightforward, the concept of high and low risk is open to interpretation based on personal experiences and values, as suggested by Parsons and Atkinson (1993).

*Numerical:*

Typically, numerical risk is often presented as percentages. For example, an at-risk couple may be told they have a 25% chance in each pregnancy of having a child with  $\beta$ TM. Risk may also be expressed in terms of probability, where couples may be informed of their 1 in 4 chance in each pregnancy of producing a child with  $\beta$ TM. The issue with this approach may be that lay people often have great difficulty in understanding and utilising numerical estimates of risk (Yamagishi, 1997), as will be shown in this chapter. This is especially so where uncertainty is intrinsic not only to the

concept of risk but also to any predictions that are made on the basis of such information, such as the risk factor for future children (Eiser, 1998).

*Graphical:*

Finally, graphical representation of risk in a pictorial format is assumed to help individuals understand and assimilate risk information in a way that would be universally understood. Pictures or drawings have been used in conjunction with other forms of risk dialogue, such as numerical and verbal descriptors in counselling sessions which, according to Hallowell and Richards (1997), would complement verbal or numerical information and enable patients to see the bigger picture and thus enable patients to gain a better understanding of their level of risk.

In order to gain an insight into the counselling session from the perspective of counsellors, I interviewed two counsellors. Although this number is insufficient to make any thematic generalisations, the purpose of these interviews was to aid contextualisation of the experiences of the mothers. However, although the participants and counsellors were asked about the availability and utilization of interpretation services where required, ascertaining the format in which genetic risk information was delivered was not explored as it was not considered to be an aim of the study. This has, in retrospect, turned out to be a weakness of the study, as incorporating more counsellors and women who had recently undergone the counselling process would have made a valuable contribution to communicative processes and power dynamics in the consultation process. However, many women, especially those who had undergone

the counselling process as far back as the 1980s, had trouble recollecting what they had been told about the trait.

Browner et al (2003), in their work on genetic counselling with women of Mexican origin, claimed that the original consumers of such interventions had changed from typically white informed women who knew what they wanted, to the present situation where women who underwent the process did so by default without knowing much about genetics and the potential relevance of the information that they were given, even after they had been counselled. These findings were also reflected in this study, which found that the inherent dynamics of the counselling session was such that women who knew very little about hereditary genetics and illness were required to assimilate a great deal of complex information. Furthermore, they were, perhaps, asked to do so at a time when they were emotionally upset, vulnerable and uncertain as to the nature of the trait and of its impact upon the 'self', the unborn child and the family at large. During the counselling sessions, in addition to risk information, participants were also offered information about prenatal tests and the management of a potentially affected pregnancy. The intensity of the counselling session was appreciated by a counsellor who was interviewed earlier on in the study.

*"We need to get across is what this thing is that she's got in her blood and what it means for her health, what it means for the health of her baby and then, what significance is the partner's haemoglobin type to hers and so the health of the baby and above all to reassure her that because she's a carrier, we're not talking about your health risk to her health or the grandparent's health who may or may not be alive. The most important message to get across to her is that 'you need to be tested to find out what the baby's going to inherit and if the baby is going to inherit a form of thal or sickle cel. It's best to know about it earlier on*



*and also out of that to get across the message to her that it's all about choice and that she should present early on in that pregnancy to get all the information, if they are found to be at risk, they can have prenatal diagnosis. They don't have to have a thal major baby, if they don't want to, so that's what we tell them. Those are the main important messages to get across to them. One importance is to get across to them the inference of this on their health and the health of their family and to dispel any worries about their health, especially if they've had previous miscarriages if this had anything to do with it. That's a lot of information to take on, you're going to get into that depth with somebody who really understands and wants to know more."*

*(Counsellor 2, London)*

This excerpt also highlights the amount of information which the participant is expected to absorb within a short timeframe in order to make pregnancy outcome decisions. Even so, regardless of the format in which counselling was provided (numerically, graphically or verbally), this study has shown that many women did not comprehend the genetic risk information they were given during the counselling process. For instance, out of 43 women, only 2 were able to repeat the "25% in each pregnancy" risk factor for thalassaemia trait with some accuracy. Discussing risk by use of ratios also led to confusion amongst many of the participants. The concept of a '1 in 4' chance in each pregnancy of a baby born with  $\beta$ TM if both parents were carriers was being interpreted as, 'if you had four children, one would have  $\beta$ TM.' This was illustrated by the following participant, who was keen that her daughter, who may have the trait, should limit her family size to avoid the possibility of having an affected child:

*"I told my daughter not to have more than two children; if she has 3 or 4 then she will be affected with a thalassaemia child maybe. I read in a book that even if she doesn't have the thalassaemia trait, she will have a thalassaemic child."*

(Participant 4. Bangladeshi Muslim aged 50. Married, at-risk couple. Four children; one son major, one daughter, possible trait.)

While it may be possible to attribute the above participant's lack of understanding of genetic risk and inheritance as a consequence of her limited English, her age and relative unfamiliarity with medical discourse, another much younger participant who grew up in England, and who had fluent English, also perceived the 1 in 4 risk factor in similar terms, as illustrated below:

*"P: It's one in four child[ren]."*

Participant 15. Pakistani Muslim age 29. Consanguineous marriage, at-risk couple. Four children, daughter major, son trait.)

Her understanding of 1 child in 4 was, in her mind, vindicated by the fact that out of four children, one - her daughter - had  $\beta$ TM.

This focus on probability or percentages seems to have resulted in making genetic risk information more complex in terms of how the participant comprehends 'actual' versus 'implied' risk. It is, therefore, necessary for counsellors to reinforce numerical representations of risk in terms of the chances of having an affected child being the same in each pregnancy, irrespective of whether the family has already had an affected child or not. This would then explain why some at-risk families may have a number of thalassaemia major children while others will not, as is evident in this study.

### 8.3 Managing genetic information

Kerr et al (1998) and Condit et al (2003), amongst others, have suggested that genetic information is not assimilated through a linear process where information is given and then assimilated, utilised and enacted upon, but occurs through a series of dynamic processes affected by socio-cultural positionings and religious beliefs. As such, it was important to ascertain how these dynamics influenced the way women derived meanings of genetic knowledge and managed the information they received during the counselling interaction.

It became apparent during the study that when women were asked to explain how they understood  $\beta$ TT, genetic risk and patterns of inheritance, the majority of women demonstrated limited understanding of these concepts. One reason for this may have been the amount of information they may have received; for example, one participant recalled the limited information she had received and the effect it had on her:

*“She gave me one sheet at the time, that’s all I can remember. It’s quite scary at the time.”*

(Participant 9. Pakistani Muslim age 24. Consanguineous married, not at-risk couple. One child, status unknown.)

The participant felt she was not given enough information and admitted to being both apprehensive about asking for clarification and afraid of the situation in which she found herself – a situation exacerbated by her poor level of English. Counsellors interviewed in this study were aware of the risk of overwhelming women with too much information when they were vulnerable and, in some cases provided, written

information or signposted them to additional resources as a way in which patients would be able to access information when it was more convenient for them - which then leads to other issues with translation and comprehension of technical genetic information.

Translation and interpretation was, in many cases, carried out by family members and this aspect was explored in relation to the relay of genetic risk information. According to Herndon and Joyce (2004), women communicating in a genetic counselling situation through a family interpreter or husband are more at risk of being given inadequate, erroneous or incomplete information. This was illustrated in the following case where a Bengali woman (speaking through an interpreter) recollected that her husband had interpreted for her during the counselling session. When asked what she presumed the trait was, she could only provide a very limited answer:

*“She says the doctor said, they told her that em...that both mother and father should have a blood test done and if both are carriers then em.... It will go on to the children. Otherwise em... so her husband...had their tests done, he was negative so he's okay so it shouldn't go to their children”*

(Participant 13. Bangladeshi Muslim age 35. Married, not at-risk couple. Five children, trait status unknown.)

Family members, and indeed husbands, have been known to act as gatekeepers and only relay information which they think is relevant and pertinent to the situation in hand. This may in part be due to their own limited understanding of the English language, as the following participant suggests:

*“I know of people within this family where the husband doesn’t know much English and neither does the wife, and they have to go to hospital, they don’t understand anything the doctor is telling them and whoever is with them tells them only the important things, not the whole story. Now every time I go to the hospital for my kidneys, there is always a woman there who will tell me what is happening, who I can talk to”.*

(Participant 10. Pakistani Muslim age 40. Consanguineous married, not at-risk couple. Five children, trait status unknown.)

Indeed, Shaw and Hurst (2009) highlight that husbands may censor information as a strategy to either protect themselves or their wives from marital insecurity (p212) or stigma. It became apparent in this study that in many cases, and especially where the women had issues of language communication, the participants’ understanding of genetic risk and genetic conditions was not increased by the genetic counselling process they had experienced (see also Middleton *et al.*, 2007). While some of the respondents, including the above participant, had very little understanding of the genetics associated with the trait, those with better communication skills in English had a slightly improved, albeit limited, understanding. Although, the participants had been through the counselling process, many women did not recollect being asked by the clinician undertaking the genetic counselling whether they had understood the information they had been given or to repeat it. Uncertainty about the trait was illustrated by the following participant when she was asked to explain the trait:

*“R: Did you understand it [genetic information]?”*

*P: Yes.*

*R: Okay, can you tell ME what you think the trait is?*

*P: (Long pause) I don't know about this, I can't understand...*

*R: Can you understand? Because you said you understood what the....  
Do you know what the beta-thalassaemia trait is?*

*P: Yes, before I'm going hospital, I'm pregnant, give blood test, find out  
I've got beta thalassaemia trait...*

*R: Did they tell you how you got it?*

*P: No.*

*R: Did they explain anything about the trait?*

*P: No, say many Asian people's got this... Doctor say Asian got too  
much beta thalassaemia. What is this beta thalassaemia...? I don't  
understand."*

(Participant 12. Bangladeshi Muslim age 36. Married, not at-risk couple. Four children, trait status unknown.)

Understanding of the trait was connected to physical manifestations; the participants realised there was a connection with their blood and assumed that their trait was due to a missing element in their blood. The majority of participants, however, had no understanding of the concept of DNA or chromosomes being responsible for the  $\beta$ TT, as illustrated by the following participant:

*"They said that there was something missing in my blood and it could  
have problems for the child that was it... I don't remember having much  
of a reaction because even before pregnancy, I still had problems with  
less blood, and the doctors used to give me iron tablets, which I used to  
take."*

(Participant 7. Pakistani Muslim age 25. Married, not at-risk couple. Pregnant with first child.)

The narrative of blood as being the medium responsible for genetic traits and illness was also suggested by the following participant, who thought that there might be something in addition to ‘blood’ such as DNA that may be responsible for her nephew’s  $\beta$ TM:

*“I didn’t know that this disease might be serious, or like this, I just thought it was only in the blood. It was only when [sister’s] son became ill then I realised”.*

(Participant 14. Pakistani Muslim age 35. Consanguineous marriage, not at-risk couple. Two children, daughter trait.)

The participant’s narrative of blood as being a vehicle for illnesses reflects anthropological literature, which discusses the strong emphasis placed on good blood in the political, cultural and religious sense. Another patient understood her  $\beta$ TT as a minor issue with the blood as opposed to a more serious issue. In the following excerpt, the idea of a “*little bit*” reflects the participant’s contextual understanding of  $\beta$ TT as opposed to a full blown genetic disease. The concept of the  $\beta$ TT was interpreted and understood by the following patient as having a smaller amount of what causes the bigger illness:

*“I knew I had a little bit [trait] and it was not dangerous”.*

(Participant 21. Pakistani Muslim age 26. Married, not at-risk couple. Two children, trait status unknown.)

Women in this study felt that their  $\beta$ TT was controllable or, at the very least, their trait could be managed so their child would not be affected. The trait management strategies among these participants followed distinct pathways according to which personal

beliefs dominated their thought processes. For example, the following Muslim participant felt that, had she known about the trait before pregnancy, she would have sought religious advice:

*“P: If I had known that I was a beta [trait] and my husband was a beta [trait], I would have been more careful.”*

*R: How would you have been more careful?*

*P: I would have asked an Islamic teacher [learned man] what kind of care I should take, what I should do.”*

(Participant 29. Pakistani Muslim age 31. Consanguineous married, at-risk couple. Three children, one major.)

On the other hand, the next participant, whose views were more dominated by Western biomedical discourse, reported that she would have turned to her GP for further advice, even though she clearly did not understand the dynamics of a trait, as illustrated below:

*“Yeah I would do actually, I would consider that if I was to get pregnant again I would go and ask what I should do, what I shouldn’t do, I think you have to take some kind of tablets or something, I’m not quite sure because she did tell me when I was expecting the baby. So yes I would.”*

(Participant 3. Pakistani Muslim aged 25. Consanguineous married, at-risk couple. One child, trait status unknown.)

As shown in the above excerpt, the participant’s inadequate knowledge of the genetic aspects of her condition and the notion of minimising risk after becoming pregnant was couched in terms of trying to minimise risk to the baby.



## 8.4 Communication during the counselling process

Although Darr (1999) has stated that it is the responsibility of the counsellor to ensure that accurate genetic information is provided in an appropriate language that the recipient can understand, Ahmad and Atkin (1996) however, argued that, on the contrary, counselling and disclosure are often undertaken by health professionals with little formal training in genetics. This is exacerbated by poor communication, limited understanding of patients' cultural backgrounds and the potential personal and socio-cultural factors that may impact upon the lives of those diagnosed with the trait. However, although there is now a better appreciation of cultural and religious diversity, communication is still a major issue, especially in the medical setting (Irshad *et al.*, 2007).

Surveys assessing adult language capacity and literacy in the UK suggest a limited ability to understand spoken English, particularly among the elderly and women of certain BME groups (Rudart, 1994). Modood et al (1997) further elaborated that the linguistic abilities of many individuals within minority ethnic groups were not at the 'survival level', at which they would be able to complete more than simple tasks in English, and especially not at the level at which they could understand medical information. However, Modood et al (1997) have also shown that healthcare professionals assume that the delivery of information in 'slower' verbal English will overcome the patient's lack of communication skills, as illustrated in the following case where a participant recalled how, despite her limited verbal communication skills, she had undergone counselling without the aid of an interpreter:

*“P: She just said there was something in my blood that could affect the baby and make something wrong with the baby if my husband has the same thing.*

*R: Did you have an interpreter with you?*

*P: No.*

*R: Why was that?*

*P: I can speak some English so she thought it was okay. And she spoke very slowly.”*

(Participant 39. Indian Hindu age 30. Married, not at-risk couple. One child, trait status unknown.)

This participant was able to give a very basic recall of the information she had received but she had attended the session without an interpreter, which was a cause for concern, although this may have been more reflective of the interpretation service availability and provision during the consultation process in the 1990s. Although in more recent times there has been an acknowledgment of the increase in diverse national languages, with some studies showing that in London alone there are approximately 300 different regional and national languages being used as the mother tongue or preferred language of communication (Szczepura, 2005; Szczepura *et al.*, 2008) which will, in turn, have additional resource implications, such as financial ones. One counsellor, although recognising the impact of resource and time constraints on the provision of interpreters, tried to overcome these by using telephone-based services such as Language-Line:

*“I use "Language-Line" although it's not a person in the office, it's over the phone. Actually I think that I'm more comfortable with "Language-Line" because it means I don't pre-book an interpreter which is a huge*

cost if people don't turn up and a waste of time for the interpreter, who could be seeing somebody else."

(Counsellor 2, London)

The two counsellors in this study also spoke of instances where, even though an interpreter had been booked, accompanying family members 'pulled rank' and usually took over translation by default as illustrated below:

*"Em... yes, her husband was there too, he did interpret for her; there was an official interpreter there as well, but they didn't need the interpreter."*

(Counsellor 1, Northern England)

The complexities of using 'informal' interpreters are well rehearsed. Not only is linguistic competence a major issue but, due to the deference many cultures show towards the medical profession, there is a danger that medics will not be challenged to provide lay terminology or in-depth explanations (Ahmed & Lemkau, 2000; Gardner & Chapple, 1999), as the following participant highlighted:

*"I know a lot of them [women] bring their family with them because they can't ask questions, they don't know what you might be saying to them, but they may and sometimes do feel intimidated with family or what they can ask you. They feel silly that "oh don't ask her that" you might have seen it. I've seen it when the husband will turn around and say "don't ask her that" and you feel that they just won't ask you anything, no matter how upset they are."*

(Participant 6. Pakistani Muslim age 30. Consanguineous marriage, not at-risk couple. Two children, trait status unknown.)

Issues arising from using family members as interpreters in genetic counselling have been previously discussed (Abdullahi *et al.*, 2009; Herndon & Joyce, 2004; Shaw & Hurst, 2009) where there is concern that families serve as gatekeepers of genetic information. How such gatekeepers understand the information themselves and, in turn, relay it to the patient is critical in determining the patient's level of knowledge and understanding of the physical manifestations and impact of a genetic trait which, in turn, will determine how the patient presents the trait information to others and avoids potential stigma (Goffman, 1958; Goffman, 1963). The following participant recalled her experience of a genetic counselling session in 2003, in which her husband acted as an interpreter. Her recollections seem to confirm aspects of information gatekeeping by her husband, as illustrated below:

*R: Who did the translation?*

*P: My husband.*

*R: Translated for you from English into Urdu?*

*P: Yes.*

*R: What did he say to you?*

*P: She just checked me and my husband and said that if one person has it then there's nothing to worry about. But if two people, both the husband and the wife, then the child will have problems. My husband didn't have it. He was normal*

*R: Did she tell you what thalassaemia is?*

*P: (nods)*

*R: What did she say?*

*P: Thalassaemia is..... She didn't really say anything to me.*

*R: She spoke to your husband.*

*P: Yes, she mostly spoke to him. She just told him that my blood was lacking in something which is why I had this."*

(Participant 7. Pakistani Muslim age 25. Married, not at-risk couple. Pregnant with first child.)

The subsequent participant told of how she had suffered physical abuse from her husband and his family following the birth of her  $\beta$ TM child. Her example highlights the potentially serious consequences of partial or inadequate information delivery by family members such as spouses (Andrews & Boyle, 2002), especially where the danger of providing inaccurate information may lead to women being stigmatised and blamed for the birth of an affected child, as indicated below:

*"I didn't know anything, I wasn't allowed to speak, my husband did all the talking. Two years after my marriage, I had my daughter, then I had him, I had problems in the house, they all blamed me for my son's condition saying you gave birth to an ill child, there is no other problem."*

(Participant 40. Indian Sikh age 40. Married at-risk couple. Three children, one major two carriers.)

Due to familial dynamics, there was the implied issue in this case that healthcare professionals were not encouraged to communicate directly with the patient (which seems to have been respected by the healthcare professional) and, as such, the participant was not in a position to be the direct recipient of genetic information, which resulted in her lack of empowerment:

*“How could anyone have asked me, no-one was allowed to talk to me.”*

(Participant 40. Indian Sikh age 40. Married at-risk couple. Three children, one major two carriers.)

Although the availability of translators and interpreters is imperative in order to provide a bridge of communication and understanding between the service providers and recipients, as well as to facilitate access to services (Irshad *et al.*, 2007), they were not always readily available, as the following participant recalled:

*“R: Do you feel you should have had an interpreter at that time?”*

*P: (Nod)*

*R: Did they not ask you if you wanted one?*

*P: We asked for one and was told that none was available.*

*R: How long ago was it?*

*P: 2 ½ years ago.”*

(Participant 36. Indian Hindu age 24. Married, not at-risk couple. One child, trait status unknown.)

This participant’s lack of understanding of the trait was further confirmed when she stated that she had understood very little of the counselling process:

*“Understand a little bit, not properly”*

(Participant 36. Indian Hindu age 24. Married, not at-risk couple. One child, trait status unknown.)

Once carrier couples are identified, a genetic evaluation in the counselling process takes place in which a family history is undertaken. This is usually undertaken in the form of a pedigree, although some researchers have advocated a 'cascade' screening system (Baig *et al.*, 2008) as a means of identifying and systematically targeting people at risk of a genetic condition. Cascade screening has the added benefit of being able to identify at-risk couples within families, which is logical given that the carrier risk of close relatives of known carriers is generally higher than the overall population risk (Krawczak *et al.*, 2001). However there is no evidence that such testing was made available to the families in this study, even where a child was diagnosed with thalassaemia major.

## **8.5 Disseminating genetic information within personal and familial surroundings**

As stated throughout this thesis, the ethos of new genetics has been to empower people by providing genetic information so that they are enabled to make appropriate choices both in marriage and reproduction. This argument could then be extended to carriers to disseminate trait information to their families enabling them i) get tested and ii) make appropriate lifestyle choices within the context of their genetic status. However, d'Agincourt-Canning (2001) debates the ownership of genetic information and whether it is a realistic assumption to assume that it is a moral duty to disseminate such information to 'biological kinships' at the risk of becoming stigmatised. Similarly, Clarke *et al* (2005) suggest that patients attending genetics clinics are often the main information gatekeepers for other family members and the decision to pass on genetic risk information should be entirely their prerogative. However, the complexity of

divulging potentially sensitive information is appreciated by social researchers such as Shaw and Hurst (2009:206), who suggest that disseminating genetic information is a complex process where disclosure of genetic risk information to relatives “*may be influenced by the nature of the condition, the potential stigma attached to it, or about their beliefs about inheriting the condition*”.

While the logic behind disseminating genetic risk information to close kin is undeniable, the space between the counsellor providing this genetic risk information and the patient assimilating and disseminating this information is a ‘grey’ area. Much of the literature on risk communication has suggested that it is not actual but perceived risk which motivates people to act in ways to benefit themselves or others (Marteau & Croyle, 1998). The disclosure of genetic risk within families is also motivated by perceptions of the severity of the risk and by a sense of perceived vulnerability (Walter *et al.*, 2004). The following participant felt that, as her trait posed no danger to her, there was little reason to inform both her immediate and extended family:

*“I think if it was a bit more serious then obviously yeah, I would have told everybody. But I mean...I'm not going to die from it, so you know....”*

(Participant 8. Pakistani Muslim age 21. Married within beradari, not at-risk couple. One child, trait status unknown.)

Another participant felt she was unable to disclose her trait, not because of a perceived lack of importance or vulnerability, but because she herself did not have a sufficient level of understanding:



*“I just know that I’ve got thalassaemia, that’s the only thing I can say because I don’t know really what the illness is, how it’s going to affect me, what it’s going to do. That’s why I don’t really talk about it.”*

(Participant 35. Bangladeshi Muslim age 30. Married, not at-risk couple. One child, trait status unknown.)

The construction of risk as a moral issue (Hallowell, 1999) in which women relinquish their right not to know about a genetic trait so that they can then disseminate this risk information to their wider families, was not very apparent in the majority of cases. The majority had been tested by default and, when asked whether they had told their families of their trait so that they could ascertain their carrier and thus risk status, most had not. Indeed, only those who had either an affected child or had disability within their own family were the ones that tended to selectively disclose their trait status to their families. The reasoning behind the decision to disclose information about the trait (or not) was mediated by many factors which will be examined in greater detail below.

## **8.6. Geographical distance and perceived lack of understanding ‘back home’**

According to Gaff et al (2005:133), disclosure of genetic test results are less likely to occur within families where members are *“genetically or socially distant, if the information is not perceived as relevant or is seen as potentially harmful to the relative.”* Social distance may be as a result of geographical distance where families do not physically meet or communicate regularly. Almost all of the women interviewed in this study had either immediate or extended family overseas whom they interacted with to varying degrees. The geographical distance between participants resident in this

country and their families ‘back home’ was considered a pragmatic reason for not causing worry to family members overseas. In addition to causing worry, there was also the issue of explaining why family members needed testing (thereby exposing their trait and drawing attention to themselves), monetary costs for testing in poor developing countries and of the perceived scarcity of testing facilities, as illustrated by the participants below:

*“R: What does your family think of thalassaemia?”*

*P: The rest of them are fine.*

*R: Have they been tested?*

*P: Baji [a term of respect] they're in Pakistan, what are they going to do?”*

(Participant 14. Pakistani Muslim age 35. Consanguineous marriage, not at-risk couple. Two children, daughter trait.)

The following participant felt that living in the UK made it easier to be diagnosed as opposed to her country of origin, Pakistan, in that not only was knowledge about beta-thalassaemia more readily available but, more importantly, so were facilities for testing and managing  $\beta$ TM. Furthermore, it may be the case that, in Pakistan and the Indian subcontinent, gender dynamics of living in a traditionally patriarchal society may mean that women may not have ready access to genetic testing or be able to understand the tests due to a lack of education, as claimed by the following participant:

*“Actually, I'm a carrier, and my husband's a carrier I mean I could like tell my brother about it as well, they could have tests as well and.... But for the wives to be tested, it's different abroad. I think it will be quite*

*difficult because they wouldn't understand, it's different for us but we live here, as for them, they live in Pakistan. They wouldn't actually understand anything like that; they probably think its some.... I don't know, they wouldn't understand."*

(Participant 3. Pakistani Muslim aged 25. Consanguineous married, at-risk couple. One child, trait status unknown.)

Contrary to this participant's belief about women in England being better placed to understand genetic information with the support of health services, this study has highlighted that many women did not understand the information they were given during counselling sessions. However, there remains a general perception that obtaining and assimilating genetic information is a bigger problem in their home countries, in part due to a lack of educational attainment in addition to the lack of testing facilities available, especially in remote areas. The following participant felt that, although her relatives in Pakistan had never heard of thalassaemia, educating them would be counterproductive since they would have very basic levels of education and would not be able to comprehend such information:

*"No they wouldn't really understand. Some people who are better educated, and have greater knowledge would understand but especially people from the village would have a lower understanding of this so explaining would be difficult. That's why I didn't say anything."*

(Participant 7. Pakistani Muslim age 25. Married, not at-risk couple. Pregnant with first child.)

One participant disclosed the fact that she had very little interaction with her relatives in Pakistan was the reason for not disseminating genetic risk information. She did not know them well enough and, therefore, she did not feel comfortable disclosing such

sensitive and potentially stigmatising information, especially as she was married within the family:

*“[I] just haven't really met them. I haven't really been to Pakistan that much in my life so we just haven't met them to talk about it.”*

(Participant 6. Pakistani Muslim age 30. Consanguineous marriage, not at-risk couple. Two children, trait status unknown.)

Personal uncertainty about the trait is interrelated with understanding of the genetic information. If a person feels that they themselves do not have a detailed understanding of the trait, then they may feel that they are not in a position to educate other family members. Moreover, as a result of this lack of understanding, the potential seriousness of the trait was not appreciated, as illustrated by the participant below:

*“I might have told them, but I was never that clear about what it was anyway. I knew I had a little bit and it was not dangerous. I never got round to it and frankly I'm not too bothered by it. I went to Pakistan for my brother's wedding and sat around talking with family members and enjoying myself, I never really thought about this.”*

(Participant 21. Pakistani Muslim age 26. Married, not at-risk couple. Two children, trait status unknown.)

This perception among the diaspora that people ‘back home’ would not understand thalassaemia due to a lack of knowledge or education is unfounded, especially in current times. Politically-led initiatives have accepted that policy input is required to prevent  $\beta$ TM; for example, in the province of Sindh in Pakistan there has been a debate, albeit a short-lived one, about banning consanguineous marriages. Public events, such as ‘Thalassaemia Days’ (organised by Thalassaemia International Federation), aim to bring

about a wider global awareness of thalassaemia and its implications. There have also been similar prevention programmes in India and Bangladesh, for example, in which the general public is becoming exposed to the condition of thalassaemia and, they are, perhaps, more aware than the participants in this study had realised. The sole occasion where a dialogue about thalassaemia did occur between a participant here and her family back home was in relation to a child of a family in Pakistan being diagnosed with  $\beta$ TM:

*“Pakistan is getting very aware of this as well. We know people whose relative had many children and they would all die. When they got to 5 or 6 months, they would die. Now they’ve had one of their children checked and he’s been found to have thalassaemia major. First they would say he had leukaemia then now in Pakistan social workers are more aware of it and spotted thalassaemia major. So now he gets treated once a month in (province of Pakistan) but Desferal is still a problem, where can you get the money from to buy that all the time? In (city in Pakistan) there are very good facilities for the treatment of thalassaemia. My uncle went and he got his transfusions from there and alhamdulillah, he’s fine”.*

(Participant 28. Pakistani Muslim age 28. Married, not at-risk couple. Three children, trait status unknown.)

This participant was aware that facilities existed in Pakistan to diagnose and treat  $\beta$ TM but, similar to the other participants, she acknowledged that the financial cost in diagnosing  $\beta$ TT or treating  $\beta$ TM can sometimes be prohibitive. In many cases these costs would be excessive as there is, more often than not, a considerable geographical distance between rural and semi-rural areas and the major cities in which these facilities are located, a situation highlighted by the following participant:

*“They won’t understand. They live in a rural area and the clinic is quite far away. Blood tests cost money...”*

(Participant 39. Indian Hindu age 30. Married, not at-risk couple. One child, trait status unknown.)

These comments throw up interesting views about the perceived lack of progress ‘back home’ regarding awareness of genetic information. Those participants who had been brought up in this country generally had little interaction with relatives in their respective home countries and thus perceived their relatives, especially those who lived in rural areas, as ‘socially backward villagers’. As such, many participants felt that it was futile to disseminate genetic information that families back home would be unable to comprehend. These notions belie the technological and social advances in terms of both prenatal testing and treatment of  $\beta$ TM occurring in the Indian subcontinent. In addition to the perception that their relatives would not understand thalassaemia and its implications was the added view that many relatives would not believe that they had, or were at risk of having,  $\beta$ TT. As reiterated in a previous section of the thesis, due to its invisibility, a genetic trait may be difficult to accept in a way that it would not if it had physical manifestations, as was confirmed by the following participant:

*“They think is silly you know, you're asking about thalassaemia. My in-laws, they don’t believe it. My mum and dad believe it but my in-laws don’t believe it.”*

(Participant 15. Pakistani Muslim age 29. Consanguineous marriage, at-risk couple. Four children, daughter major, son trait.)

The above excerpt illustrates the possible conflict between her parents’ support and her in-laws disbelief, which then has implications for managing her daughter’s  $\beta$ TM.

## 8.7 Perceived lack of importance

Heshka et al (2008:19) concluded in their systematic review that the behavioural changes in people tested for genetic risk were short-term. They also argue that there were “*no differences (in behavioural change) between carriers and non carriers by 12 months after genetic test and over time the risk perception decreased.*” It can be on the basis of this argument that, while the antenatal screening and prenatal testing process is underway, the anxiety and stress associated with uncertainty would be enough to keep the trait high on the personal agenda. However, as a trait is asymptomatic, the importance attributed to it appears to diminish over time (especially if there is little or no risk perceived), as illustrated by the participant below:

*“But we don’t make an issue out of it because really I don’t have that much because it doesn’t affect me in that respect. I don’t have any physical problems with it; it’s not obvious so why talk about it? It doesn’t affect you that much it probably doesn’t even come into any discussion as much as it probably would if you were like a thalassaemia major or something because you’re always at some stage in your life having to do something to deal with it you know for life like blood transfusions or seeing a doctor and that.”*

(Participant 43. Indian Hindu age 20. Single.)

The above participant’s perceptions of the importance of risk are similar to couples who are also not at risk of producing  $\beta$ TM children;  $\beta$ TT then becomes a non-issue and is relegated to the periphery of daily life.

## 8. 8 “Minding our own business”

Contrary to Hallowell’s (1999) argument that women who attend genetics clinics perceive themselves as having a responsibility to their kin (past, present and future generations) to establish the magnitude of their risk and the risks to other family members, the majority of women in this study chose to act otherwise. The perception of risk was not considered serious enough, nor did there seem to be a perceived moral responsibility to disseminate the information to their kin. When asked about why they chose not to inform their families, in addition to the reasons already given three women explicitly mentioned that their personal distance from their families warranted their desire not to interfere in family matters, as illustrated by the following participant:

*“They [family] don’t interfere in each others’ business... We’ve never discussed our personal issues with each other...”*

(Participant 21. Pakistani Muslim age 26. Married, not at-risk couple. Two children, trait status unknown.)

This sentiment is in contradiction to the assumption that South Asian families are unified, close-knit, and supportive of each other – a myth often perpetuated by the South Asian communities themselves (Atkin *et al.*, 2004). However, this ‘closeness’ and perceived obligation to share sensitive information was not reflected at all in this study. Instead, participants highlighted the complexities (shared by other majority populations) of sharing information (confirmed by Shaw and Hurst (2009), especially where respect, gender, power relationships, geographical distance and fear of stigmatisation played a vital part in deciding whether to divulge potentially sensitive information about oneself. It was therefore considered easier by some participants to



withhold such potentially stigmatising information by inferring that one would rather not get involved in family politics, as suggested by the participant below:

*“It’s mum’s side of the family that are like, the carriers and em... I don’t know Asian families... you’d rather not get involved. Yes, it’s just not worth it you know... you telling them something and they think ‘yuck!! She’s telling us we’ve got a disease’ or you know; they’re really funny. So I’d rather just keep out.”*

Participant 37. Pakistani Muslim age 26. Consanguineous marriage, not at-risk couple. Two children, trait status unknown.)

The above participant alluded to the stigma she felt she would have to face (Goffman, 1963) had she revealed her trait status. In addition, the emotional hassle and implications of exposure may “*not [be] worth it*”.

## **8.9 Empowerment by providing earlier diagnosis**

There is an assumption by public health specialists and providers of genetic tests that if those at risk are informed of their trait status earlier in life, they will then be enabled to make proactive decisions at crucial points in their lives, such as choosing a marriage partner or reproductive choice (Petersen, 1998). However, of participants who had early knowledge of their trait (n=10), only three women indicated that they had explicitly requested partner testing prior to marriage. These three participants viewed their trait in a ‘matter of fact’ clinical manner and utilised the information in the way that is encouraged by the healthcare profession:

*“I actually knew before I was married that I was carrying that and I actually told my husband that “look this is what I’ve got, you need to go and get yourself checked out because if you are a carrier, then obviously*

*our kids will be affected...” so I was really open about the fact. So that’s what he done, he had a full blood test done.”*

Participant 8. Pakistani Muslim age 21. Married within beradari, not at-risk couple. One child, trait status unknown.)

*R: When you were growing up with it, before you got married, did you ever think about having your husband to be tested?*

*P: Yes I did.*

*R: Where was he, did he come over from Pakistan?*

*P: No he lived here in this country, and he did have a blood test.*

*R: Before the marriage?*

*P: Yes.”*

(Participant 11. Pakistani Muslim age 37. Married, not at-risk couple. Four children, trait status unknown.)

*“Well I told him that I had thalassaemia trait...em.... And if he's got it then obviously our children will suffer and I mean he didn't mind, he had the test done.”*

(Participant 2. Pakistani Muslim aged 32. Married, not at-risk couple. One child, disabled and trait.)

Although these participants did request testing, they did so based on practical grounds where they had enough understanding of the trait to know of its reproductive implications. In addition, all three participants married spouses who already lived in the UK so perhaps they did not need to negotiate additional layers of intra-cultural gatekeeping and face potential stigma, as may have been the case with overseas spouses as seen in other studies (Hussain, 2005).

Socio-cultural constraints, including the fear of stigma and courtesy stigma (Goffman, 1963), prevented the majority of women in this study from disclosing their trait status even if they were aware of it before marriageable age.

Even so, one participant spoke of how she had broken off her engagement to her fiancé after his test results showed he too carried the trait. Although she alluded to the fact that his trait status was only part of the reason in pre-empting a possible affected pregnancy, it did provide her with the extra impetus to enable her to end the relationship, as illustrated below:

*“P: And em.... I was engaged at that point to one of my cousins and he had a check and I don’t really remember whether he had it or not, but my sister’s partner, he had it, he was checked, he had it so we em.... Just broke off the engagement.*

*R: Because of the trait?*

*P: Yeah, one of the reasons.”*

Participant 2. Pakistani Muslim aged 32. Married, not at-risk couple. One child, disabled and trait.)

This participant was illustrating the phenomenon of using genetic information to manage social situations to her advantage, which has previously been highlighted by Ghanei et al (1997).

## **8.10 Empowerment by ensuring access to information**

Although sociologists in general may tend to disagree with the medicalisation of the pregnant body, for example Rothman (1986), as well as the female body in general (Oakley, 1988), genetic testing has been heralded as a vehicle for empowering women by giving them access to crucial information about their bodies (Parthasarathy, 2007) and thus enabling them to make the relevant choices. Therefore, a key requirement for women who go and get tested for genetic conditions is that there should be a support

mechanism enabling them to access the knowledge required for informed decision-making in light of the dynamics of the testing process and diagnosis.

Access to information is vital if people affected by medical conditions are to become more proactive in managing those conditions (Hallowell, 1999; Petersen, 1998). Indeed, the current political emphasis towards self-management in the form of the 'expert patient' programmes (Department of Health, 2001a) requires that, in addition to emotional support, relevant and comprehensive information needs to be accessible in order for patients or carers to effectively self-manage long-term conditions. With regard to this study, the fieldwork was originally when the NHS Sickle Cell and Thalassaemia Screening Programme was in its infancy and, as such, the only information available to women at that time was that which was given during the screening consultation. As expected, none of the participants who had had their children in the 1980s or 1990s recalled being given any written or verbal information about thalassaemia. In addition, information booklets, whilst being available in multi-language formats from agencies such as the UK Thalassaemia Society and local thalassaemia charities, had not filtered down to the participants. None of the participants in this study (who had undergone the counselling process up until the end of data collection in 2003), recognised the booklets that I showed them in different South Asian languages, nor could they recall being given any kind of supplementary information during the counselling session. This gap in knowledge had consequences not only for positive action in the management of the  $\beta$ TT but also for the prospects of empowering those women, who may not have been in a position to question their

healthcare professionals at the point of counselling. In addition, this lack of information also impacted upon the participants' children in that, in many cases, the women were unaware that their  $\beta$ TT children could have issues at certain critical points in their lives, such as marriage or reproduction. One participant, who tried to overcome the gap in knowledge after her trait diagnosis, was able to do so because she was a science student at that time and, thus, in a position to actively seek information to enhance her knowledge and understanding, as she revealed below:

*“As soon as I found out I had thalassaemia trait I then went to several thalassaemia talks. They had talks on at colleges, to find out what it was about. I got books and I went down to the Thalassaemia Society, which is in London.”*

(Participant 6. Pakistani Muslim age 30. Consanguineous marriage, not at-risk couple. Two children, trait status unknown.)

Another participant revealed that she had ‘picked up’ information she found in the local library:

*“R: Do you try and find out as much as you can about it?*

*P: Yeah. If I see some information about thalassaemia, I just pick the leaflets up.*

*R: Do you actually try..... I mean if you see something..... I mean do you actually go into a library and try and find some books about thalassaemia?*

*P: Yeah, here I got two books from there.*

*[shows me 'The Politics of Sickle Cell and Thalassaemia' and another general book]*

*R: When did you start finding out as much as you could about it?*

*P: Em... since last year.*

*R: Why?*

*P: If I see anything on sickle cell or thalassaemia, I just pick it up.”*

(Participant 15. Pakistani Muslim age 29. Consanguineous marriage, at-risk couple. Four children, daughter major, son trait.)

Despite the case that this participant actively sought information, the information she found in the form of academic textbooks was in many ways inaccessible as her level of English was basic and it was. therefore, debatable if these resources would have enabled her understanding of  $\beta$ TT and her management of her daughter's  $\beta$ TM.

As this study sample highlighted, language skills have a direct impact upon the ability to comprehend and manage not just genetic aspects of  $\beta$ TT that would permit comprehension of the hereditary aspect of the illness but also the chronic illness aspect of  $\beta$ TM. Current initiatives such as The Department of Health's Expert Patient Programme (Department of Health, 2001a) have been promoted as the way forward in the proactive management of one's own or a child's long-term chronic illness, with patients and families being taught how to better manage their condition by specially trained peers in their own language, in addition to being supported by the community matron. However, access to information is as pertinent now as it was when the research data were collected. The skills needed to become an expert patient may not be easy, especially for women who may have issues with communication and marginalisation, and patient groups such as the UK Thalassaemia Society have voiced scepticism about the value of such programmes in managing conditions such as  $\beta$ TM (personal communication UK Thalassaemia Society, 2010). Furthermore, many organisations have their own websites, such as the NHS Sickle Cell and Thalassaemia Screening Programme and Healthtalkonline (<http://www.healthtalkonline.org/>), which has a wide

array of information about many conditions available to the public and much of it is available in different languages. The issue, however, is that the accessibility of such avenues of information remains questionable as it assumes that potentially marginalised women have a high enough degree of literacy, both technological and linguistic, to be able to access and navigate around these sites and to comprehend what may be technologically advanced information without the input of a healthcare professional (Lorence & Park, 2006). Although the participants in this study did not have access to potentially similar sources of information, as they might have had if they had been diagnosed in present times, the question remains whether women today are accessing such information, to what extent and in what context, and whether language skills have sufficiently progressed to enable them to take a proactive stance.

### **8.11 Implications for service delivery**

The issues highlighted in this chapter have implications for the appropriate and culturally competent delivery of screening services. Education is believed by service providers and policy planners to be the front line tool for engaging the public with awareness programmes and enabling them to make reproductive choices (engaging with organisations such as the Genetic Interest Group). In the context of raising awareness about genetic illness, mass education was seen as an important method of educating people about  $\beta$ TT and  $\beta$ TM without the danger of stigmatising women, as pointed out by the following participant:

*“I couldn’t have asked for my husband to get tested before our marriage even though his family are very nice, they would have been very worried.”*

*It's a good thing that people know about this and educating the public is the best way to do it".*

(Participant 39. Indian Hindu age 30. Married, not at-risk couple. One child, trait status unknown.)

Other participants stressed that potentially marginalised women should become the focus of information delivery as a way of both educating and empowering them (see for example: Crotser & Dickerson, 2010; Middleton *et al.*, 2005), as illustrated by the following participant:

*"... the ones that are brought from over there ... they can't speak the language, they're locked up inside... how the hell are they ever going to find out? Their husbands talk to the doctors and probably don't understand themselves, can't be bothered explaining to the wives, come home, go to bed... have a baby with thalassaemia major and say whoops what happened. It's nice to know that people are trying, but I don't see anything changing".*

(Participant 37. Pakistani Muslim age 26. Consanguineous marriage, not at-risk couple. Two children, trait status unknown.)

One participant also commented on the dissonance in the communication process between providers of prevention programmes and their recipients and the need for information in the recipient's preferred language:

*"If these women take people to the clinic with them, then you should give the information to them in Urdu. So they can read it themselves, if there's a nurse who speaks Urdu or a doctor in the clinic then that's good too."*

(Participant 7. Pakistani Muslim age 25. Married, not at-risk couple. Pregnant with first child.)



Although this situation has been, to a large extent, rectified in recent times with an emphasis on providing adequate translation and interpretation, in addition to training link workers to act as the bridge between providers and recipients in illnesses such as diabetes (Saxena *et al.*, 2007), the prevention of  $\beta$ TM can only be enabled if communication and cultural barriers are overcome and thalassaemia becomes part of public discourse in a similar way to heart disease and diabetes, a point highlighted by the following participant:

*“I don’t think people are very much aware of thalassaemia as they would be of say for example cancer or diabetes and things like that and so most people don’t have a clue what it is.”*  
(Participant 43. Indian Hindu age 20. Single.)

Although there is a present day emphasis on trying to involve religious leaders by setting up programmes in temples or mosques, such as the diabetes and heart disease prevention interventions in Scotland (Ghouri, 2005), much of the success has been due to the outreach by link workers rather than involving the religious leaders themselves. However, it is debateable whether the success of diabetes and heart programmes can be replicated in the management of a potentially stigmatising condition, such as a hereditary disorder, within the religious setting. Chinouya and O’Keefe (2005), in her work with HIV management within religious spaces, suggests that, despite the importance of faith in the management of daily life within the context of a positive HIV diagnosis, the church is construed as a threatening space marked by a lack of confidentiality and a site for the generation of stigma. By their very nature, South Asian and, more specifically, Muslim religious spaces tend to be predominantly occupied by

men and, as such, it is of little surprise that none of the women in this study mentioned targeting mosques or temples for outreach work on the awareness of genetic illnesses.

Interestingly, there emerged during the interviews a certain level of cynicism among some of the participants about the lack of motivation to change from within the community, which reflects views held by many healthcare workers about the unwillingness of BME groups to become proactive in the prevention and management of their illnesses:

*“I think our people...like the gore [white people] think we don’t really bother. It’s quite true in one way, I think our Asian people, we really don’t care about these kinds of things.”*

(Participant 3. Pakistani Muslim aged 25. Consanguineous marriage, at-risk couple. One child, trait status unknown.)

Again, another participant compared South Asians to ‘pindoos’ (illiterate, unsophisticated villagers) in terms of attitudes towards health promotion:

*“I think a lot of them just try to ignore the whole situation. I think they’re just behaving like pindoos [illiterate people] to be quite honest.”*

(Participant 2. Pakistani Muslim aged 32. Married, not at-risk couple. One child, disabled and trait.)

In another context, following the interview with his wife, the husband of one of the participants conveyed his frustration about his mother and wife’s lack of proactive interaction with healthcare professionals early enough to tackle their ailments:

*“You know one thing that I really hate about our Asians is that... My grandmother and aunty and my missus here, she doesn’t know what we’re talking about, but one thing I hate do you know one thing about our relatives is that if something’s wrong with them, if they’re ill, when you mention going to the doctor, they get scared. “No, no I’ll be alright”. But problems like serious problems for example headache, she’ll have a headache and I’ll say lets go to the doctor to see what’s going on, they say “no I’ll be alright.” And when the pain’s like really increased and they say I can’t bear it anymore and then that’s the time when you take them to the doctor and then that’s the time when they also have treatment. You know what I mean, they want treatment but other than that what I believe in if there are small signs in any disease or anything you should get treatment then, cos in the early stages, there may be a chance of a cure. When it’s too late... that’s when they go.”*

(Husband of Participant 16. Pakistani Muslim age 20. Consanguineous marriage, at-risk couple. One child, possible major.)

## **8.12 Conclusion**

This chapter has highlighted and discussed many aspects of how the knowledge of a genetic trait was assimilated and disseminated by South Asian women. Undertaking an exploration into the dynamics of genetic screening and counselling, I sought to ascertain the way in which genetic information was conveyed from the healthcare professional to the participant. The issue of communication of such potentially complex information was also investigated, as was the situation with regard to interpretation and translation. This study found that the vast majority of women in this sample had a very low level of understanding of the hereditary implications of their trait.

The socio-cultural and religious dynamics of managing pregnancies within at-risk couples were also analysed. This analysis included the reference points women used when deciding whether to undergo prenatal screening, with many at-risk women using

religious references to decide on whether to continue their pregnancy as well as any future reproductive decisions.

The medical model of genetic risk and responsibility was also analysed and the study showed that, contrary to healthcare professionals' expectations, the majority of women in this study did not disseminate genetic risk information within their own families or to their in-laws. They cited many reasons for this, such as the fear of getting involved within families, or their perceptions about the level of education, knowledge and finances of relatives 'back home'.

Finally, with regard to thalassaemia being specifically targeted in health promotion programmes, I established that, at the time of conducting this study, when genetic risk awareness programmes were still in their infancy, promoting the prevention of a potentially stigmatising (genetic) disorder would not have been successful, especially in religious settings, and that a more proactive approach involving women themselves would be required.

In the final chapter, I will draw together the key arguments of this study in an attempt to answer the main research objectives and include a discussion of the methodology and further recommendations.

## **CHAPTER NINE: DISCUSSION AND CONCLUSIONS**

### **9.1 Introduction**

This final chapter will discuss the main findings arising from the analysis chapters and how these are supported by the relevant literature. I will then go on to provide a reflective account of the appropriateness of the chosen methodology and how this may differ if the study was to be conducted again. This is then followed by a discussion of how this study has contributed to theoretical knowledge and finally of research and policy recommendations.

### **9.2 The impact of stigma**

Erving Goffman defined stigma as ‘the process by which the reaction of others spoils normal identity’. Although Goffman (1963) recognised stigma in three forms, namely; mental illness, physical deformity and an undesired differentness, the current study has shown that genetic traits if revealed, can also lead to stigmatisation from others. While not a physical illness, in South Asian cultures, a genetic trait can be adversely viewed as a factor which may affect a women’s ability to fulfil her expected role which is heavily defined by her culture. A woman’s place in what is essentially a pronatalist culture requires her to be able to bear and give birth to healthy children. However it is when a women’s ability to produce healthy children is threatened, then stigma can have a profound impact upon the way she manages this ‘undesirable attribute’.

This study highlighted the perceived stigma which could be salient at various stages of women’s lives; for example before marriage where a prospective bride-to-be could be

subject to scrutiny about her health if her trait were to be disclosed. Participants consistently spoke of what was expected of them in terms of being good daughters, going into good marriages and becoming mothers of healthy children and the personal and social consequences if those expectations were not met. This was highlighted by a participant who voiced the concern that females would remain unmarried if such conditions were disclosed. These cultural practices appeared to be just as inherent amongst migrant South Asian communities as it is on the Indian subcontinent. For example, in Talbani and Hasanali's (2000) study in which they explored the experiences of South Asian females living in Canada showed that expectations of females as 'good' daughters wives and mothers are still maintained by cultural practices and any dissent from those norms and values could lead to a high personal and social cost. 'Good' is not necessarily meant here in the moral sense but more in terms of the complete and undamaged physical wholeness which would produce the future generations. The production of healthy generations is dependent on 'good' blood.

Although women in this study did not necessarily understand the hereditary aspects of 'blood', they did nevertheless realise that the  $\beta$ TT was something in their blood and therefore liable to be stigmatised. This finding confirms Goldachre's (2010) who found that illnesses with a genetic basis are more likely to cause stigmatisation as opposed to those which can be explained by environmental factors. This belief was apparent in the majority of participants who feared the social and personal consequences if their trait were to be revealed, especially as it was blood related.

The current study also found that women were blamed and stigmatised for producing an affected child irrespective of whether they were part of a consanguineous or non-consanguineous marriage. This finding contradicts Darr's (1990) study which suggests that consanguineous families knew they would be criticising their own blood if they criticised those mothers and therefore, by implication, consanguinity acted as a buffer against blame and stigma who gave birth to  $\beta$ TM child. However, the present research demonstrated that the women's identity within the family was negotiated by the trait (and blame) as opposed to familial ties (and protection). This study also showed that even within consanguineous families, there was an element of labelling which stigmatised family members who had BTM as 'them' as opposed to a genetic trait which could be hidden as 'us'. This finding is supported by Link and Phelan's (2001) understanding that labelled individuals are placed in distinguished groups that serve to establish a sense of disconnection between 'them' and 'us'.

Women in this study employed various strategies to avoid being labelled and as a result stigmatised, one such strategy involved concealing the  $\beta$ TT completely from family members and the general community. Participants who chose to do that regarded the invisible nature of the trait as opposed to a physical disability as a way of facilitating this concealment. Others engaged in selective disclosure, for example, disclosing the minor symptoms of anaemia associated with being a carrier of the  $\beta$ TT, thereby downplaying the hereditary aspects of the condition.

### 9.3 Managing genetic information

This study highlighted the various scenarios in which the  $\beta$ TT diagnosis was made, the dominant experience of trait diagnosis being during ante natal screening. Many of the women were informed of their trait diagnosis by letter which, in many cases, they did not understand and had to have translated by husbands or other family members. They then had to contend with how their partner (who would also have to undergo blood tests) would react to that news. Although none of the participants highlighted this as a major issue, I was nevertheless aware that the ‘it was okay’ stance could have arisen as a result of my identity as a South Asian researcher and the need, thus, to save face. There were, however, diverse experiences when partner blood tests were being considered. In some cases women did admit that, although they had tried to convince their partners to undergo tests, that was not possible in all cases either because the husbands refused to have their blood tested or because they were overseas. The premise of ante natal screening and pre natal tests is that genetic information should enable an ‘at risk’ couple to make an informed decision as to how to avoid or manage an affected pregnancy. Although, there were only two counsellors interviewed in this study, there was found to be a discrepancy between the process of ante natal screening described by the health care professionals and the perceived reality of the participant’s experience in screening, as described by them. For example, two women felt rushed through the process of partner testing without any time to assimilate the information provided to them. Another participant felt she was ‘steered’ towards termination through the information that was presented to her by the counsellor which caused her distress. Ahmed *et al* (2008) in their study of Pakistani and European women argued that



decision making with regards to pregnancy management is a complex process and in many ways is similar across the ethnic groups in question. In the context of this study, diversity in managing at risk pregnancies was also apparent. Some of the participants made autonomous decisions while other women delegated decision making to senior members of the family in respect of cultural norms. In this way, the women demonstrated tensions in trying to retain cultural values 'back home' while trying to demonstrate independent decision making (Shaw, 2000). One issue that remained salient throughout this experience was that the women tended to be isolated either due to the fact that natural support structures, such their own families, were 'back home' or as a result of communication difficulties in English. With a few exceptions most women dealt with this by themselves without much emotional support. In terms of managing 'at risk' pregnancies, decision making does not occur in a vacuum but is dependent on the participant's religious beliefs in refusing prenatal testing and termination (see Atkin et al, 2008). However, the couples in this study who claimed that they would terminate an affected pregnancy were not part of an 'at risk' couple and those who were 'at risk' felt compelled to wait and see. Many spoke of the emotional turmoil they felt as they waited for test results, fearful for the implications for both themselves and their babies. If their husbands tested negative then understandably not only was this was a huge relief for them but they could also put it to the back of their minds and forget about it.

Eleven women in the sample were part of consanguineous marriages. Supporting Darr's view (2005), that consanguinity debate diverts attention away from the real

minority ethnic health issues and the design and delivery of responsive health services to minority ethnic populations, the participants reported that consanguinity was used by health care professionals as a way to attribute the cause of abnormalities. Many participants expressed confusion about the validity of the consanguineous argument as it did not explain consanguineous marriages that they were aware of and which produced unaffected children and children with  $\beta$ TM born from non-consanguineous marriages. Similar to Shaw and Hurst (2008), this study found that health professionals stigmatised consanguineous marriages particularly amongst the Pakistani participants and as a result the participants would react to this focus on consanguinity by not disclosing that they were part of a consanguineous union in health settings (thereby avoiding possible stigma). Of importance however, this study found that the stigma of consanguinity arose not only from out with Pakistani communities, but from within them as some participants voiced their disapproval of blindly following the practice without considering the implications.

#### **9.4 Caring for a child with thalassaemia major**

This study highlighted that the time when women are at risk of major sanctions and stigma from her partner and her in-laws is when she gives birth to a child with  $\beta$ TM. Due to the overt physical manifestations of  $\beta$ TM and the frequent and invasive treatment regimes, women were no longer in a position to conceal their trait. Six women who had a child with  $\beta$ TM spoke of being singled out as the cause for their child's illness by both their partner and their in-laws and, sometimes, even by their affected child as they were considered responsible. Although Shaw and Hurst (2008;

2009) have suggested that this may be due to a lack of biological knowledge about X and Y chromosomes, I would suggest it has as much to do with gender politics, patriarchal societies and a lack of empowerment for women, with the result of blame being levelled at the weakest members. There was a marked difference in experiences between those women who had an affected child and those who did not in terms of quality of life, socio-cultural impact and religious involvement as a coping strategy.

Women who had children with  $\beta$ TM tended to assume the role of primary carer. Although there is much evidence to suggest that there are universal aspects in caring for a chronically ill child, irrespective of culture, such as the gendered caring role and the financial and emotional impact (Atkin & Ahmad, 2000a; Nuutila & Salanterä, 2006), this study builds on this work and enhances social scientific knowledge by revealing the cultural dynamics of caring for a child with thalassaemia major within South Asian families in England. For instance, the mothers in this study tended to face pronounced isolation within their family unit. Not only were they providing almost all of the care for their child, even in an extended family situation, but the majority of mothers asserted that they also had to contend with active hostility from both their spouse and extended family as a result of producing an affected child. In addition, South Asian women in the UK and, in particular, the mothers of children with thalassaemia major, were additionally vulnerable due to the marginalisation, communication issues and deprivation. Van den Tweel and colleagues (2008) who measured Health Related Quality of Life among European parents of chronically ill children and found the quality of quality of life was poor. In this study, I have shown that participant's quality of life

can be adversely affected by marginalisation caused by poor communication problems, deprivation, isolation and a lack of access to resources.

Sapountzi-Krepia *et al.* (2006) examined the emotional and financial impact of routine hospital admissions for chelation therapy for children. In suggesting that mothers faced a heavy psychosocial burden, which was exacerbated by healthcare providers' assumptions of familial support available to Greek families, their findings reflected the experiences among the mothers in this study. The traditional assumption that South Asian families will 'look after their own' was not prevalent in the present research, since the mothers did not feel supported in caring for a child with thalassaemia major within the extended family (See also; Katbamna *et al.*, 2004).

## **9.5 The role of faith as a coping strategy**

This study also examined the role of religion: how South Asian women made sense of their child's  $\beta$ TM, and as a consequence, of their own  $\beta$ TT. Atkin and Ahmad (2000a) demonstrated that turning to religion was an extremely important strategy for African-Caribbean and Muslim parents in coping with their child's haemoglobinopathy. The present study has added to this finding by showing that religion, although important to Muslim mothers as a support mechanism, was also critical for Sikh and Hindu mothers of children with  $\beta$ TM. Faith provided a theoretical framework in which to make sense of, and pragmatically accept, illness. Women who had children with  $\beta$ TM drew upon their faith for strength and meaning - although their child was suffering, so were they as the mothers of that child. Muslim, Hindu and Sikh mothers viewed both their own and

their child's suffering as being a test from God, which then enabled them to make meaning of it and to cope with their ill child and the consequences arising from that (such as stigma, blame and isolation as highlighted in the previous section). Faith also provided a proactive stage by which to pray for resolution and good health - findings which are echoed in other studies (see for example; Woodward & Sowell, 2001).

Although religion played a dominant part in the coping strategy of mothers with  $\beta$ TM children, other women drew on their faith during crucial points in their life such as to cope with the uncertainty of the screening process, as one participant did when she performed an intense prayer for guidance about whether her husband should undergo blood tests for  $\beta$ TT. There was no evidence in the current study that the mothers utilised formal support in the form of imams or priests. This is not surprising as, traditionally, religious spaces have tended to be male-dominated and generally considered inappropriate in which to discuss personal matters. In addition, as Chinouya and O'Keefe discovered in their study of Africans with HIV, there is a general mistrust of religious leaders (2005), a finding echoed by Denham (2002) in his work with young British Muslims. The concept of a temple or mosque as provider of active community support is one that is recently being advocated with the onset of public health programmes utilising religious spaces, especially after prayer times, to carry out health promotion work or for example diabetes screening (Ghouri, 2005). Perhaps there is scope for religious spaces to be used for initiatives that promote genetic screening or programmes specifically targeted towards males.

## 9.6 Delivering genetic information

This study found that the majority of participants did not understand the genetic information they were given during their consultations. The participants reported being unable to understand or recollect genetic information which may in part have been due to them receiving this information as far back as the 1980s, making it difficult to recall their experiences. However, the most salient observation was that women were unable to understand the way in which the risk factor was conveyed. For instance, many participants interpreted the ‘1 in 4 chance in each pregnancy of having a thalassaemia major child’ across the pregnancies rather than within each pregnancy with the result that some women thought limiting the size of their families would avoid a child with  $\beta$ TM. Communication of genetic risk was exacerbated further as a result of limited English communication skills amongst the South Asian sample which made it difficult to assimilate complex information during the counselling session (for example, see Middleton et al, 2007). Furthermore, managing genetic information in the present research contradicts the assumption that understanding develops in a linear form where information is given, assimilated and utilized (Kerr et al, 1998; Condit and Bates, 2005). Instead, as suggested by other researchers (for example Atkin et al 2008, Shaw and Hurst 2008, Shaw and Hurst, 2009), the process of managing genetic information was influenced by factors such as socio-cultural and religious beliefs among the South Asian women. This was highlighted in this study which found that many women were unable to explain their understandings of the trait, patterns of inheritance and the potential consequences. Suffice to say that the belief that knowledge of the trait and its potential consequences would compel at-risk women to become proactive in suggesting potential

partners be screened (Petersen, 1998) was not evident in this study. This in part confirms recent work by Petrou (2010), whose recent study in India suggested that, even when both members of a couple are diagnosed as being at risk, they may go ahead with marriage despite the risk of giving birth to affected children, which is contrary to premarital couple testing programmes initiated in many countries both in Europe and in the Middle East.

Indeed, communication was and still is an issue in the medical setting (Irshad et al, 2007). This is exacerbated by language barriers and lack of formal training in genetic counselling amongst health care professionals (see also Qureshi et al, 2006).

## **9.7 Disseminating genetic information**

The ethos of new genetics is to empower people by providing genetic risk information so that they can make appropriate choices in the management of their health and their families. However, this view does not take into account that the disclosure of genetic risk within families is motivated by perceptions of the severity of the risk and perceived vulnerability of the trait carrier (Walter *et al.*, 2004), as evidenced among some of the women in this study. Although studies by Shaw (Shaw, 2000) and Baradwaj (2003) indicate that privacy may be a factor in withholding genetic information from families, this study has shown that other factors found to affect the dissemination of genetic information was the general view that it was futile to discuss genetic risk information as family members would not be able to understand this knowledge, testing facilities were not always available and were too expensive. However, this perception of ‘back home’

as being 'backward' is unfounded in present times (compared to when the research was conducted) due to the economic, technological and social advances that have recently taken place in India, Bangladesh and Pakistan - changes that would be conducive to prevention and management of hereditary traits. These societal changes mean that 'culture' back home may also have changed towards the perceptions of genetic screening (Baig *et al.*, 2008). It is interesting however, to consider that an additional reason for the women's inaction may be that by not disclosing genetic risk information, the participants were in fact, concealing the disclosure of potentially stigmatizing information which could impact their identities and taint them as having a discreditable attribute (Goffman, 1963).

The nature of this research study showed the symbolic interactionism perspective where South Asian women made sense of the  $\beta$ TT within the context of their everyday lives. Women acted according to their perceptions of how others would perceive them if their trait were to be disclosed and as a result they presented and constructed the trait in order to preserve the 'self' within the context of their everyday life experiences. So far I have described the main findings arising from the analysis chapters and how these are supported by the relevant literature. For example I have discussed how Goffman's theory of stigma was a major element in how participant's managed their trait in order to limit the emotional and physical effects of stigma. I also discussed how women managed their pregnancies in light of being diagnosed as a trait carrier and the dynamic around decision making for at risk couples especially within consanguineous marriages. Then I discussed the implications of having a child with BTM, which was isolating and



extremely difficult for the mothers. Faith acted as a support mechanism that not only provided support for women both during decision making during pregnancy and when having to care for a child with BTM. This study also showed that delivering risk information was problematic in the sense that women quite often did not understand the format in which it was delivered with potentially serious consequences. In addition women were reluctant to inform their families of their risk factors and thereby discouraging testing within the family.

## **9.8 Methodological reflections**

In this section I will provide a reflection on the methodological aspect of this study. This study employed a modified grounded theory strategy. I described the philosophical underpinnings of the chosen methodology and research design which was influenced by symbolic interactionism in Chapter Four. Due to the nature of the study, I felt that a qualitative design would be more appropriate as it would allow flexibility in the holistic exploration of the emergent themes in a sensitive study. Semi-structured interviews were utilised due to the flexibility they allowed in exploring emerging issues. Establishing a multilingual dialogue with participants allowed the establishment of trust and rapport which was necessary to facilitate discussion of sensitive topics and sometimes traumatic experiences. The interview schedule allowed the exploration of issues arising in the interviews as well as providing empirical evidence of the significance of culture, religion and gender dynamics in the day-to-day management of the  $\beta$ TT.

In chapter five, I deliberated the dynamics of the research process with marginalised populations, especially during the post-September 11<sup>th</sup> political environment, which was not particularly conducive to potentially intrusive and sensitive research. I also established that, although my many identities (South Asian, Pakistani, Muslim, and mother) were pivotal in establishing contact with participants and gaining access to conduct interviews, they impacted the research process in both positive terms such as they enabled a connection with my participants which then allowed for the exploration of sensitive issues, and negative terms in which participants may not have disclosed information for wanting to 'save face' and gave culturally acceptable responses when discussing issues such as termination.

Even though native researchers are accused of not possessing the same level of objectivity as a non-native researcher because their cultural/ethnic identity may mean they are too close to the subject matter to form an 'objective' view (Ahmad, 2003), I remained aware of the need for objectivity throughout the study. Although, instinctively, I was sympathetic towards 'my own people', especially in light of the negative scrutiny Muslims were facing after September 11<sup>th</sup>, I was faced with the dilemma of either 'sanitising' my data to prevent of negative stereotypes many have of Muslims or to report the data and aim for balance. However, after a period of self-reflection (as discussed in chapter 4), I decided on the latter.

As I retrospectively evaluate the research process I undertook, especially in light of my subsequent experiences as a researcher in sensitive studies, I am aware that the changing nature of ethical research would not allow me to repeat many of the successful

recruitment methods I undertook, for example, recruiting participants for the study directly by accessing their medical information. Whilst I have already discussed the issues that emerge from the 'opt-in' approach, I am nevertheless aware that that this approach makes it difficult to recruit minority or marginalised populations who may require a more proactive approach than that currently deemed appropriate by research ethics committees.

The 'two pronged' recruitment strategy including utilising both formal and informal approaches worked well. The informal approach was particularly important during the post 9/11 socio-political environment where people were particularly distrustful of strangers asking questions. Upon arriving in the interview setting, I was able to draw upon my multiple identities to find common ground and establish rapport, which resulted in the production of rich data sets. However, there were instances in which I felt viewed with subtle suspicion, which was especially apparent in one interview setting in which the participant refused to allow the audio recording of the interview. It goes without saying that as researchers evolve and gain confidence in the research setting, different philosophical underpinnings and methods of collecting data are then able to be utilized, such as mixed methods whereby both quantitative and qualitative methods could be combined in one study.

An evaluation of the research design and process confirmed that the strategies chosen for both methodological design and carrying out the fieldwork were the most appropriate at that particular moment in time. The modified Grounded Theory strategy was important as it enabled emergent theories to be grounded in the actual data and it

was the participants' stories that were heard. However, in retrospect, if I were to conduct this particular study again, I would chose a mixed-method strategy by incorporating a questionnaire in which those delivering antenatal services and genetic counselling would be surveyed as to their perceptions of the services they deliver to minority ethnic communities. This, in combination with the interviews, would have provided a more in-depth and rounded study. I have, as a researcher, learned many valuable lessons: practical ones such as designing and managing a qualitative-based study including gaining confidence in the research ethics application and governance procedure and the sometimes very difficult issues in recruiting people from marginalised populations; personal lessons were learned, which included how to better manage sensitive interview settings and maintain a professional stance while retaining my natural empathy towards the women in this study; in facing emotional participants, I learned to deal with my own emotions when confronted by distressed participants and harrowing stories. It is these lessons which have enabled me to develop both as a researcher and a mentor and undertake studies in areas such as end of life and paediatric cancer.

## **9.9 Original contributions to theoretical knowledge**

The aim of this study was to explore the understandings of the meanings of the  $\beta$ TT among South Asian women in England in the context of their everyday socio-cultural and religious experiences and identities. In this way, it is argued here that the thesis has made original contributions to the literature, both empirically and theoretically, and this occupies the following discussion.

Although there has been subsequent research using interviews, observations and survey methods published in this field (see for example: Ahmed *et al.*, 2008; Atkin *et al.*, 2008; Shaw & Hurst, 2008; Shaw & Hurst, 2009), this study has supported, complemented and made original contributions to the current understandings of how women of South Asian origin make meanings of, and manage knowledge of, the  $\beta$ TT. This thesis both followed and diverged from other theses in thalassaemia such as those by Darr (1990) and Ahmed (2000). Whereas both Darr and Ahmed focus primarily on Pakistani populations in northern England using a limited language range, this study recruited from multiple sites throughout London, West Midlands and northern England. In addition, this study utilised diverse languages such as English, Urdu, Punjabi, Hindi and Sylheti as opposed to the limited range employed in previous studies. Due to its proximity to 9/11, this thesis provided unique insights into the recruitment process and data collected from the point of view from a defensive population. By utilising semi-structured interviews and undertaking literature searches, this study has made a contribution to knowledge in areas such as:

- Management of a potentially discreditable attribute: Goffman's Stigma theory (1963) was used to provide an overall framework as to how a trait was perceived, managed and understood by women of South Asian origin. Although stigma has been touched upon by Shaw and Hurst, this study illustrated how women actively utilised strategies to minimise the potential stigma which they would face if their  $\beta$ TT was to be discovered. It showed how women linked the trait to more common conditions such as anaemia, making them more

acceptable, which is a finding not replicated elsewhere. In circumstances where  $\beta$ TT was disclosed, its hereditary implications were hidden to prevent stigma in a pronatalist culture. In addition, women were very much aware of the concept of ‘courtesy stigma’ and the impact it would have on their siblings’ chances of attaining good marriages if their  $\beta$ TT was disclosed.

- Apportion of blame: Subsequent to the study by Darr (1990), this study highlighted different dynamics within consanguineous marriages. In contrast to Darr’s (1990) findings, there was no difference in the apportioning of blame for having a child with  $\beta$ TM within consanguineous or non-consanguineous marriages; women were still subject to blame and familial sanctions even in consanguineous marriages.
- Perceptions of risk: Much of the available literature on the perceptions of genetic risk is focused on communities other than South Asian. This study has investigated the concept of risk to women of South Asian origin who were diverse in socio-economic status, education, religious, geographical and age backgrounds and found that, irrespective of these diverse backgrounds, women perceived risk in similar ways. This study provided empirical evidence that women were unable to understand the way in which the risk factor was conveyed. For instance, many participants interpreted the ‘1 in 4 chance in each pregnancy of having a thalassaemia major child’ across the pregnancies rather than within each pregnancy. As a consequence, many women thought that they could avoid a child with  $\beta$ TM by limiting the size of their families.

- Dissemination of genetic information within families: Shaw and Hurst (2008; 2009), in their observational study of Pakistanis highlighted that familial delivery of genetic information within Pakistani families is based on people's own contextual notions of what constitutes hereditary disorders and their origins, as well as inter-familial dynamics. This study illustrated that some participants expressed hostility towards close relatives who had  $\beta$ TM, viewing them as tainted regardless of their own invisible  $\beta$ TT. This study also showed that although dissemination of genetic risk within Pakistani, Indian and Bangladeshi families was dependent on the socio-political dynamics within families themselves, with many women not disclosing genetic information for fear of stigmatization or cultural repercussions, there was an outdated perception of whether this information would be of any use in the participant's home countries. Many women had families 'back home' to which they did not disclose such information as a result of outdated beliefs of healthcare provision, lack of public awareness and technological advancement. These participants have illustrated the 'time warp' tendencies of the South Asian diaspora in that they do not appreciate the changing nature of 'back home' in terms of awareness programmes, screening and treatment of  $\beta$ TM. Participants in this study, acting as custodians of genetic information, managed that knowledge by choosing not to disclose it to their families overseas and, in doing so, prevented attention becoming focused on themselves as carriers of a hereditary trait.

- An evaluation of the wider spectrum of experiences of  $\beta$ TT: Writers such as Darr (1990) have commented on the impact within families of  $\beta$ TM children, Ahmed evaluated the concept of informed consent during screening (2000) and subsequently the use of religious belief in pregnancy management and termination (2006, 2008) and, most recently, Shaw and Hurst have evaluated the understandings of genetics, illness causality and inheritance among British Pakistani users of genetic services (2008; 2009). This study has sought to provide, for the first time, a holistic picture of the experience of the  $\beta$ TT for the women of Indian, Bengali and Pakistani origin who were from diverse socio-demographic backgrounds. It sought to ascertain the impact of  $\beta$ TT from the moment of diagnosis through to the comprehension, management and dissemination of genetic information within a social and cultural context.

## **9.10 Further research and policy recommendations**

This study has identified gaps in research knowledge which necessitate further analysis such as:

- The issue of understanding and thereby managing risk information for women of South Asian origin, or indeed BME women in general, require further consideration. This study highlighted the dissonance between what the counsellor meant and what the participants understood in terms of genetics and the risk of having an affected child. The women in this study had a very limited grasp of the '25%' or '1 in 4' chance in any pregnancy concept. This clearly has



implications for at-risk couples in how they negotiate areas of reproduction and management of pregnancy. Although there is theoretical knowledge in risk perception in the public realm, there needs to be a focus on populations at high risk of hereditary disorders who are marginalised in terms of socio-economics, citizenship and communication issues.

- Further research needs to be carried out with Black and Minority Ethnic men and how they understand hereditary recessive disorders. Although there has been recent work incorporating limited views of Pakistani men (Shaw & Hurst, 2008; 2009), there is very little information about how, for example, Indian or Bangladeshi or Middle Eastern men (who are also high risk groups) perceive genetic traits. Currently there is very little theoretic knowledge within the public realm as to how men absorb, comprehend and manage genetic information, especially if they are part of an at risk couple. Although this study did not seek to understand the meanings of a hereditary trait for men, I was asked many times by the partners of participants why they were being marginalised in the research process. In communities where there is a gender power imbalance, it becomes imperative to involve men not only as partners in the screening process itself, but to target men in public awareness campaigns. There is, therefore, a need to ascertain conceptual understanding of the meanings men in high risk communities per se make of genetic information in order to provide culturally competent and appropriate initiatives.

- To ascertain the efficacy of initiatives such as Expert Patient Programme and community matron programmes in providing the culturally-appropriate education, training and support to people with  $\beta$ TM and their families.

### 9.11 Implications for service delivery

Although the data for this study were collected at a particular moment in time in 2002-2003, the experiences narrated by the participants carry relevance for service delivery today. The NHS Sickle Cell and Thalassaemia Screening Programme was implemented to provide systematic screening on a universal basis which would overcome issues of ethnic targeting and identify thalassaemia carriers early enough to enable informed decision-making about pregnancy management. However, a recent study by Dormandy et al (2008a) showed that women were still not being screened before the target time of 10 weeks, which would have allowed enough time to make an informed choice as to managing an affected pregnancy. In addition, an evaluation of the NHS Sickle Cell and Thalassaemia Screening Programme showed that, although the programme was in general successful, there remained areas which required attention (Musson & Rogers, 2009). For example, there remained a limited awareness of sickle cell and thalassaemia within both the healthcare services and at-risk populations (p10). As highlighted in the current study, Musson and Rogers (2009) still found that GPs, in addition to feeling under-qualified to deliver genetic information, were unaware of the screening timelines and their importance. Musson and Rogers (2009) also highlight that, within the range of printed information available to at risk women, *“underpinning concepts such as genetic inheritance are complex and difficult to explain and in some cultures are*

*difficult to translate*” (p16). This was highlighted earlier in this study (chapter three), where I discuss the difficulty in finding the appropriate terminology to explain hereditary traits to research participants as a result of their lack of knowledge about these issues.

Although the NHS Sickle Cell and Thalassaemia Screening Programme has set up initiatives such as a steering group that includes both carers of and people with  $\beta$ TM, community outreach sub-committees, the ‘Pegasus’ resource ([www.pegasus.nhs.uk](http://www.pegasus.nhs.uk)) which provides a resource and training for screening professionals and information for the public, materials in community languages in the form of DVDs and audio-visual materials on websites, there is little evidence that this is filtering through to the community. Certainly, ongoing contact with parents of  $\beta$ TM children who are undergoing blood transfusions has confirmed that, even today, many parents had never heard of beta-thalassaemia until they gave birth to an affected child.

Even though there is culturally and linguistically appropriate information available online on sites such as [www.healthtalkonline.org](http://www.healthtalkonline.org), this information is still only available to people who know how to access it and not for potentially marginalised women who have language and communication issues as in the current study. In the evaluation of the NHS Sickle Cell and Thalassaemia Programme, Musson and Rogers (2009) make an important point that there is a need to make wider use of the grassroots knowledge of the voluntary sector (e.g. The United Kingdom Thalassaemia Society and North of England Bone Marrow and Thalassaemia Association) in their work with local communities. Put simply, the Programme needs to adopt a more culturally sensitive

approach to raise public awareness of thalassaemia and to establish outreach programmes that are long-term and sustainable, which is especially pertinent in the current climate. In addition, any education or awareness programme needs to be delivered with a blame-free and culturally sensitive approach so as not to disenfranchise high-risk populations. For example, there needs to be a shift in the focus on consanguinity as a reason for poor birth outcomes which has the potential to alienate at risk communities such as Pakistani Muslims or Middle Eastern populations for example, and provide information that allows communities to make *choices* in their reproductive health such as pre-conception counselling, preimplantation diagnosis (where embryos are screened before implantation) or IVF, rather than try and change their cultural practices.

Health policy directives and technological advances in the treatment of  $\beta$ TM discussed in the introduction have the potential to impact the way in which mothers of children with  $\beta$ TM perceive their own  $\beta$ TT. NHS initiatives such as The Expert Patient Programme (EPP), with the combination of community matrons, has the potential for  $\beta$ TM to be managed as any other long-term chronic condition. The EPP began to be piloted early in 2002 (Bury, 2002) during the data collection phase of this study, so no participant had been affected by these initiatives at that time. It is therefore feasible to suggest that women who had  $\beta$ TM children in present times, would be better psychologically and practically supported than they were during the time of this study. However, general evaluations of EPP and community matron programmes still suggest that accessibility, and cultural competence may be an issue (Greenhalgh, 2009; 2007).

## 9.12 Conclusion

This thesis, has illustrated that the comprehension and management of genetic information is a complex process. Women of South Asian origin not only managed, understood and utilized knowledge of  $\beta$ TT within the remits of their social and cultural perceptions, but they actively used strategies to avoid being labelled and stigmatized. Genetic risk information was delivered in a way that was incomprehensible to the majority of women which has implications for how 'at risk' populations understand and make use of this information to proactively prevent affected births. In contradiction to the ethos of informed consent and dissemination of genetic information which families, women were reluctant to inform family members of possible genetic risk which has implications for the screening of family members prior to pivotal events such as marriage.

This thesis takes forward the argument that the genetic consultation needs to be paid more attention because it is a crucial aspect of how people and especially women will deal with the knowledge of a genetic trait for present and future pregnancies. Future research and related policy recommendations need to focus on providing appropriate and culturally sensitive public education programmes, sensitive screening and to further improve the delivery of genetic risk information especially to marginalised communities enabling them to better manage and enact upon genetic knowledge.

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## APPENDICES

### Appendix 1: Characteristics of participant Sample

Participant Number	Characteristics
P1	Pakistani Muslim aged 23. Married, not at risk couple. Two children, trait status unknown. Educated to college level. Husband bus driver. Lives as part of nuclear family.
P2	Pakistani Muslim aged 32. Married, not at risk couple. One child disabled and has trait. Educated to high school level. Husband self-employed businessman. Higher income. Lives as part of nuclear family.
P3	Pakistani Muslim aged 25. Consanguineous marriage; at risk couple. One child, trait/thalassaemia status unknown. Educated to high school level. Husband manually employed. Lives as part of nuclear family
P4	Bangladeshi Muslim aged 50. Married, at risk couple. Four children; one son major, one daughter with trait. The participant has an MA from Bangladesh. Husband is a clinician and is current resident overseas. Participant lives with her children.
P5	Pakistani Muslim age 38. Married within beradari, not at risk couple. Four children; trait status unknown. The participant has a BA from Pakistan. Her husband is currently unemployed, claiming benefits. Lives as part of nuclear family, however extended family live in cross proximity.
P6	Pakistani Muslim age 30. Consanguineous marriage, not at risk couple. Two children, trait status unknown. University educated in the UK. The participant is employed in a clinical related field. Lives as part of nuclear family.
P7	Pakistani Muslim age 25. Married, not at risk couple. Pregnant with first child. Educated to high school level. Works as a receptionist in the NHS. Lives as part of nuclear

	family.
P8	Pakistani Muslim age 21. Married within beradari, not at risk couple. One child, trait status unknown. Educated to primary school level in Pakistan. Husband is involved in the retail trade. Lives with husband's parents.
P9	Pakistani Muslim age 24. Consanguineous married, not at risk couple. One child, status unknown. Educated to high school level. Husband self employed businessman. Lives with husband's parents.
P10	Pakistani Muslim age 40. Consanguineous married, not at risk couple. Five children, trait status unknown. Educated to primary school level in Pakistan. Husband is a technician. Lives as part of nuclear family.
P11	Pakistani Muslim age 37. Married, not at risk couple. Four children, trait status unknown. University educated in the UK. The participant is employed in a clinical related field. Lives as part of nuclear family.
P12	Bangladeshi Muslim age 36. Married, not at risk couple. Four children, trait status unknown. Educated to primary school level in Bangladesh. Husband is employed in the catering trade. Lives as part of a nuclear family.
P13	Bangladeshi Muslim age 35. Married, not at risk couple. Five children, trait status unknown. No education. Husband unemployed. Lives as part of a nuclear family.
P14	Pakistani Muslim age 35. Consanguineous marriage, not at risk couple. Two children, trait status unknown. Educated to primary school level. Husband is a taxi driver. Lives as part of a nuclear family.
P15	Pakistani Muslim age 29. Consanguineous marriage, at risk couple. Four children, daughter major, son trait. Educated to high school level. Husband unemployed. Lives as part of a nuclear family.



P16	Pakistani Muslim age 20. Consanguineous marriage, at risk couple. One child, possible major. Educated to primary school level. Husband works in a call centre. Lives as part of a nuclear family.
P17	Bangladeshi Muslim age 24. Married, not at risk couple. One child, trait status unknown. Educated to primary school level. Husband unemployed. Lives as part of a nuclear family.
P18	Indian Muslim age 32. Married, not at risk couple. Three children, trait status unknown. Educated to college level. Employed in childcare arena.  Lives as part of a nuclear family.
P19	Pakistani Muslim age 27. Married, not at risk couple. Two children, trait status unknown. Educated to primary school level. Husband is employed in a manual setting. Lives as part of a nuclear family.
P20	Pakistani Muslim age 34. Consanguineous marriage, not at risk couple. Three children, trait status unknown. Educated to primary school level. Husband is self-employed. Lives as part of a nuclear family.
P21	Pakistani Muslim age 26. Married, not at risk couple. Two children, trait status unknown. Educated to primary school level. Husband is employed in computing. Lives as part of a nuclear family.
P22	Indian Hindu age 23. Married, not at risk couple. Two children, trait status unknown. Educated to primary school level. Husband is employed as a technician. Lives as part of a nuclear family.
P23	Indian Sikh age 43. Married, not at risk couple. Three children, trait status unknown. Educated to university level. Husband is self employed. Lives as part of a nuclear family.
P24	Indian Sikh age 25. Married, not at risk couple. One child, trait status unknown. Educated to university level. Husband

	is employed in sales. Lives as part of a nuclear family.
P25	Pakistani Muslim age 30. Married, not at risk couple. Three children, trait status unknown. Educated to university level. Husband is employed in sales. Lives as part of a nuclear family.
P26	Pakistani Muslim age 20. Married within beradari, not at risk couple. One child, trait status unknown. Educated to university level. Husband is employed in sales. Lives as part of a nuclear family.
P27	Bangladeshi Muslim age 50. Separated from trait husband. Six children; one major, one trait. No education. Lives with children.
P28	Pakistani Muslim age 28. Married, not at risk couple. Three children, trait status unknown. Educated to high school level. Employed in housing. Lives as part of nuclear family.
P29	Pakistani Muslim age 31. Consanguineous married, at risk couple. Three children, one major. Educated to primary school level in Pakistan. Husband is employed in IT. Lives as part of a nuclear family, but extended family lives in close proximity.
P30	Bangladeshi Muslim age 25. Married, not at risk couple. One child, trait status unknown. Educated to primary school level. Husband is employed on a casual basis. Lives as part of a nuclear family.
P31	Bangladeshi Muslim age 21. Married, not at risk couple. Two children, trait status unknown. Educated to primary school level. Husband is employed in a manual capacity. Lives as part of a nuclear family.
P32	Bangladeshi Muslim age 21. Married, not at risk couple. Two children, trait status unknown. Educated to high school level. Husband is unemployed. Lives as part of a nuclear family.

P33	Pakistani Muslim age 26. Consanguineous marriage, not at risk couple. Two children, trait status unknown. Educated to high school level. Husband is unemployed. Lives as part of a nuclear family.
P34	Bangladeshi Muslim age 19. Married, not at risk couple. One child, trait status unknown. Educated to primary school level. Husband is employed on a manual capacity. Lives with extended family (husband's).
P35	Bangladeshi Muslim age 30. Married, not at risk couple. One child, trait status unknown. Educated to primary school level. Husband is unemployed. Lives as part of a nuclear family.
P36	Indian Hindu age 24. Married, not at risk couple. One child, trait status unknown. Educated to primary school level. Husband is employed in sales. Lives as part of a nuclear family.
P37	Pakistani Muslim age 26. Consanguineous marriage, not at risk couple. Two children, trait status unknown. Educated to college level. Husband is employed as a builder. Lives as part of a nuclear family.
P38	Bangladeshi Muslim age 20. Married, not at risk couple. No children.  Educated to high school level. Husband is employed in sales. Lives as part of a nuclear family.
P39	Indian Hindu age 30. Married, not at risk couple. One child, trait status unknown. Educated to college level. Husband is self-employed in retail. Lives as part of a nuclear family.
P40	Indian Sikh age 40. Married at risk couple. Three children, one major two carriers. Educated to primary school level. Separated from husband. Lives with her children.
P41	Indian Hindu age 52. Married at risk couple. One child, major. Educated to university level. Husband is employed in

	engineering. Lives as part of a nuclear family.
P42	Indian Hindu age 45. Divorced, not at risk couple. Three children, status unknown. Educated to high school level. Employed in casual manual work. Lives as part of a nuclear family.
P43	Indian Hindu age 20. Single. Current status is as a student.
P44	Counsellor
P45	Counsellor

## Appendix 2: Generic interview schedule for participants

QUESTIONS	FOLLOW – ON QUESTIONS
Before you were told you were a carrier, had you ever heard of thalassaemia?	Media  Family knowledge  Medical setting
Tell me about how and when you came to be told?	Prior to marriage  During pregnancy
Talk me through the process of what happened?	Dynamics of the screening process
Did you understand the nature of the blood tests before having them?	Information  Informed consent
Were you invited to meet a counsellor?	Process of communication

What ethnic group did the counsellor belong to?	Cultural awareness Participant perception of counsellor
How did you both communicate with each other - was there an interpreter present?	Communication of genetic information
Did you feel you could communicate well with your counsellor?	Communication, interpretation understanding
Did you feel your counsellor understood your needs/fears/concerns?	Cultural, personal, religious empathy
Do you understand how you have become a carrier?	Assimilation of genetic information
How do you feel about being a thalassaemia carrier?	Meanings
Have you told anyone about being a carrier?	Dissemination of genetic information Stigma

If yes to whom and why?	
If no, why not?	
Do you think being a carrier has affected your life?	Impact on personal life and on roles such as motherhood,wife
Have you told members of your family - not your partner?	Stigma
How /what did you tell them?	
Did they understand about how you are a carrier and how it may affect you?	
Have you told your husband/partner?	

If yes what was his response?	
If no why not?	
Has he had a blood test?	
What was the result?	
If you husband/partner turns out to be a carrier do you understand how this may have an affect on your unborn child?	Understanding of counselling process
Will this affect the way in which you wish to manage your pregnancy?	Management of pregnancy



Why?	
Do you have other children?	
Are any of them carriers or does anyone have thalassaemia major?	
Do you understand why/how your child is affected?	Understanding genetic information
How do you feel about that?	
How does your husband/partner feel about the trait?	
How does the general family, in-laws, parents etc feel?	

Have these experiences affected your religious beliefs?	
If you had known about thalassaemia before marriage/pregnancy etc., what would you have done if anything?	<p>Utilisation of genetic information</p> <p>Informed decision making</p> <p>Empowerment</p>
How did you feel when I contacted you for interview?	Feelings about the interview process
Is there anything you feel I should have asked that I did not?	
Is there anything you want to know about the issues we have discussed?	

### **Appendix 3: Draft of letter to consultants**

[University headed paper]

Dear.....

Your details were provided by (haemoglobinopathy counsellor) whom I had contacted in relation to a research project I am conducting.

I am a research student at DeMontfort University, Leicester and have embarked on a project which will investigate and analyse the psychological, cultural, religious and social impact to South Asian women who are carriers of the beta-thalassaemia trait. In order to verify my status, you may if you wish contact my supervisor, Dr Simon Dyson at:

Department of Health and Applied Social Sciences  
De Montfort University,  
Scraptoft Campus,  
Scraptoft  
Leicester LE7 9SU. Telephone: 0116 257 7751  
E-Mail: [sdyson@dmu.ac.uk](mailto:sdyson@dmu.ac.uk)  
<http://www.tascunit.com>

For this study, I would like to conduct interviews with carriers, haemoglobinopathy counsellors and other health personnel such as yourself. The interviews would be semi-structured and will focus on the screening process for haemoglobinopathies as well as well as the understanding that Asian women have of the beta-thalassaemia trait. I hope that by conducting such interviews we may begin to understand more about the health needs of such women, and how well a diagnosis of the thalassaemia trait is understood. In this way the research may be able to make suggestions for further improving service provision

I would therefore appreciate it if you would be able to give me approximately half an hour to 45 minutes of your time to discuss these issues. If I may, I would like to phone your office in a few days time to schedule an appointment.

Thanking you in advance

Yours faithfully

Tasneem Irshad

## **Appendix 4: Letter to participants**

[University headed paper]

[Date]

[Address]

Dear [name],

The social meanings and implications of the beta-thalassaemia trait  
among South Asian women in England

I am a research student and am writing to ask if you would be willing to consider taking part in an interview study which is being run by De Montfort University, Leicester and supervised by Dr Simon Dyson.

This study is going to interview South Asian women (those who have family origins in India Pakistan or Bangladesh) who have been told they have the beta-thalassaemia trait. It is important to understand, what you know of this trait and how it has affected you (if at all).

I will call you in ten days to talk about the study and to answer any questions you may have before you decide to take part. It is your choice on whether you take part in this study. If after talking to me you decide not to take part, this will not affect any treatment that you are having or will have in the future. If you agree to take part, you will be interviewed once, for about 30-60 minutes, at a place and time which suits you.

Please take time to read the information that has been sent with this letter. If there is something you don't understand, you can ask me when I call you.

Yours sincerely

[Name]

Enc.

## **Appendix 5: Information sheet**

[University headed paper]

### **INVITATION TO PARTICIPATE IN A RESEARCH PROJECT**

The social meanings and implications of the beta-thalassaemia trait among

South Asian women in England

My name is Tasneem Irshad and I am a research student wishing to undertake the above study

I am writing to ask you to consider taking part in an interview study by De Montfort University about women's experiences of the beta-thalassaemia trait. This study has been given ethical approval and is being undertaken in collaboration with .....Trust. The study is being sponsored by De Montfort University Department of Health and Applied Social Sciences, Scraptoft Campus, Scraptoft, Leicester LE7 9SU.

To help you make up your mind about taking part, please read the following information:

#### **What is the purpose of the study?**

This is an important study because South Asian women have not been asked about the impact the carrier status has on their lives (if any) and because it will try and find out information such as the best way to provide genetic information to people of South Asian communities, to see how such information is understood within the cultural, familial and socio-political context and to understand how carriers interpret their understandings of their carrier status.

#### **Why have I been invited?**

You have been identified as being told you have the beta thalassaemia trait by your medical records and hospital consultant as well who are helping us with this research.

### **Do I have to take part?**

It is up to you to decide. If you do take part I will discuss the study with you and ask you to sign a consent form before I interview you. You are free to withdraw from the study at any time, without giving a reason. This would not affect the standard of care you may receive. I will follow up this letter with a phone call to you in 10 days to answer any further questions and to see if you wish to take part.

### **What will happen to me if I take part?**

If you agree to take part, I will arrange to come and see you for an interview. The interview can be held at a place and time that suits you. Often people prefer to be interviewed in their own homes but we can make other arrangements if that suits you better.

In the interview I will ask you to talk about your experiences of having the thalassaemia trait and the impact it has had on your life – if any.

Your interview will probably last for between 30 and 60 minutes. It will be audio-recorded and I may write some notes as you speak. After the interview I will make a written transcript of the audio recording which I will use to analyse the data coming from all the interviews.

### **Are any medicines or treatments involved in this study?**

No, this is simply an interview study to tell me more about your experiences.

### **What are the possible disadvantages and risks of taking part?**

While you may find the interview reminds you of worrying times, most people will find it straightforward. Some people find it helpful to have the opportunity to talk about issues like this.

### **What are the possible benefits of taking part?**

Taking part in the study will not lead to additional tests or treatment for you. We hope the knowledge gained will help improve screening and service provision in the future for you and for others.

**Will my taking part in the study be kept confidential?**

Yes. Returned forms, audio recordings and written transcripts will all be stored securely. Only I will be able to access them. When the findings of this research are published, I may use a quote from your interview, but if we do this it will be in such a way that no-one can tell who said it.

**What will happen if I don't want to carry on with the study?**

You are free to withdraw from the study at any time. If you withdraw after the interview, I will destroy the audio recording and written transcript of your interview.

**What if there is a problem?**

Any complaint about the way you have been dealt with in the study will be addressed. If you wish to speak to someone about this you can contact: Dr Simon Dyson, De Montfort University Department of Health and Applied Social Sciences, Scaptoft Campus, Scaptoft, Leicester LE7 9SU. Telephone 0116 257 7751

## Appendix 6: Written consent form

Title of research proposal: The social implications and meanings of the beta-thalassaemia trait among South Asian women in Britain

REC Number:

Name of Participant (Block Capitals):

Address

Please initial or tick box

1	The study organisers have invited me to take part in this research	<input type="checkbox"/>
2	I understand what is in the leaflet about the research. I have a copy of the leaflet to keep.	<input type="checkbox"/>
3	I have had the chance to talk and ask questions about the study	<input type="checkbox"/>
4	I know what my part will be in the study and I know how long it will take	<input type="checkbox"/>
5	I know how the study may affect me. I have been told if there are possible risks	<input type="checkbox"/>
6	I understand that I should not <b>actively</b> take part in more than one research study at a time	<input type="checkbox"/>
7	I know that the local Research Ethics Committee has seen and agreed to this study	<input type="checkbox"/>
8	I understand that personal information is strictly confidential:  I know the only people who may see information about my part in the study are the research team or an official representative of  the organization which funded the research.	<input type="checkbox"/>
9	I understand that for the purposes of transcription and analysis, my interview will be tape recorded. However only the researcher will have access to these tapes which will be destroyed upon completion of	<input type="checkbox"/>



	the study	
10	I understand that my personal information may be stored on a computer. If this is done then it will not affect the confidentiality of this information. All such storage of information must comply with the 1998 Data Protection Act.	<input type="checkbox"/>
11	I know that the researchers will/might tell my general practitioner (GP) about my part in the study	<input type="checkbox"/>
12	I freely consent to be a subject in the study. No-one has put pressure on me	<input type="checkbox"/>
13	I know that I can stop taking part in the study at any time	<input type="checkbox"/>
14	I know if I do not take part I will still be able to have any treatment that I am currently having	<input type="checkbox"/>
15	<p>I know that if there are any problems, I can contact:</p> <p style="text-align: center;">Dr/Mr/Ms.....</p> <p>Tel. No. .... Bleep No./Ext. ....</p>	<input type="checkbox"/>

\_\_\_\_\_  
Name of Participant

\_\_\_\_\_  
Date

\_\_\_\_\_  
Signature

\_\_\_\_\_  
Name of Researcher

\_\_\_\_\_  
Date

\_\_\_\_\_  
Signature

## **Appendix 7: Field Notes**

Participant:

Interview date:

No of Interview:

Venue:

Language interview conducted in:

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